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Is Information Property? Distinctive Genetic Information Has an Answer

KUMIKO KITAOKA *

INTRODUCTION

Senator Elizabeth Warren became a victim of the former president's mockery when she took a DNA test to support her claim of Native American heritage.¹ The senator publicized the test result as evidence of her "unadmixed Native American ancestor . . . in the range of 6-10 generations ago."² Unfortunately, the announcement also caused a backlash from Native American communities.³ The Cherokee Nation issued a statement that tribal citizenship is based upon centuries of their traditions, not DNA tests.⁴

Ancestry testing like the senator's is offered by commercial companies.⁵ Beyond commercialized testing, genetic and genomic ("genetic/genomic") analysis is conducted for a variety of reasons.⁶ For example, genetic/genomic research examines genetic/genomic variations among organisms to identify morbidity-related genetic/genomic changes so that life-saving treatments can be created.⁷ The increasing volume of data from genetic/genomic studies translates into accelerated data use.⁸ In the field of genetics/genomics, size and diversity are often a key to success.⁹ As such, databases are merged and shared among institutions.¹⁰

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1. Glenn Kessler, *Just About Everything You've Read on the Warren DNA Test Is Wrong*, WASH. POST (Oct. 18, 2018), <https://www.washingtonpost.com/politics/2018/10/18/just-about-everything-youve-read-warren-dna-test-is-wrong>.

2. *Id.*

3. The tribes consider DNA as an inseparable part of a person. Charles Petit, *Trying to Study Tribes While Respecting Their Cultures / Hopi Indian Geneticist Can See Both Sides*, SFGATE (Feb. 19, 1998), <https://www.sfgate.com/news/article/Trying-to-Study-Tribes-While-Respecting-Their-3012825.php>; Astead W. Herndon, *Elizabeth Warren Apologizes to Cherokee Nation for DNA Test*, N. Y. TIMES (Feb. 1, 2019), <https://www.nytimes.com/2019/02/01/us/politics/elizabeth-warren-choerokee-dna.html>.

4. See Herndon, *supra* note 3.

5. See Kessler, *supra* note 1.

6. See *infra* Background: Tomorrow is a Mystery [hereinafter Background].

7. Amy L. McGuire & Laura M. Beskow, *Informed Consent in Genomics and Genetic Research*, 11 ANN. REV. GENOMICS & HUM. GENETICS 361, 362 (2010).

8. See *infra* Background Section B.

9. McGuire & Beskow, *supra* note 7, at 362.

10. See *infra* Background Section B.

Inasmuch as genetic/genomic technologies have gained importance, concerns over the misuse of sensitive information have grown.¹¹ PCR (genetic) testing has become a routine practice for the protection of human lives from COVID-19 infection; however, it has also created the problem of stigmatization, privacy, and profiling.¹² The Cherokee Nation's reaction to the senator's test announcement indicates that a person's DNA test might affect the solitude of another person or a well-defined population.¹³

Not so long ago, scientists at Arizona State University (ASU) conducted unconsented genetic research on the Havasupai Tribe (ASU Incident).¹⁴ The researchers used the samples for a migration study and later published the results without specific permission.¹⁵ To the Havasupai Tribe, it was not simply an unauthorized disclosure of personal information, but it approximated the destruction of their legacy.¹⁶ The incident gave rise to a million-dollar lawsuit against ASU.¹⁷

In spite of the lessons learned from the ASU Incident, it is becoming common to use genetic/genomic information beyond the originally disclosed purposes.¹⁸ From the perspective of participants' privacy and autonomy, the ASU Incident is a great illustration of why genetic/genomic information presents such a challenging issue—the highly-exploitable and unlimited nature of use, the identifiability of a tissue donor, and the multiplicity of

11. See *infra* Background Section C.

12. See *FBI Investigating COVID-19 Data Breach in South Dakota*, AP NEWS (Aug. 21, 2020), <https://apnews.com/article/cfdcf0b77303664b165faf4866887612>; see also PRESIDENTIAL COMM'N FOR THE STUDY OF BIOETHICAL ISSUES, PRIVACY AND PROGRESS IN WHOLE GENOME SEQUENCING 24-25 (Oct. 2012) [hereinafter PRIVACY AND PROGRESS]; McGuire & Beskow, *supra* note 7, at 367.

13. The Cherokee Nation does not determine its race by reference to DNA testing. Herndon, *supra* note 3.

14. The university researchers also collected samples from the Havasupai Tribe for a study of diabetes and used the samples to study their ancestry. Robyn L. Sterling, *Genetic Research among the Havasupai: A Cautionary Tale*, 13 AM. MED. ASS'N. J. ETHICS 113 (2011). See also Nanibaa' A. Garrison, *Genomic Justice for Native Americans: Impact of the Havasupai Case on Genetic Research*, 38 SCI. TECH. & HUM. VALUES. 201 (2013); Kristof Van Assche et al., *Protecting Dignitary Interests of Biobank Research Participants: Lessons from Havasupai Tribe v Arizona Board of Regents*, 5 L. INNOVATION & TECH. 55 (2013).

15. Sterling, *supra* note 14, at 115.

16. See *infra* Argument: Quasi-property Right as Non-Common Privacy Interest [hereinafter Argument] Section C. 2.

17. See *id.*

18. McGuire & Beskow, *supra* note 7, at 373.

interested parties.¹⁹ Aggrieved participants may initiate privacy tort actions.²⁰ However, it is hard to prevail in tort-based actions or resolve grievances through existing mechanisms.²¹

Previously published articles have outlined ethical, legal, and social issues involving the collection and use of genetic/genomic data and have indicated that there is no one-size-fits-all approach.²² Among the proposed solutions against the offensive use of genetic/genomic information is the introduction of property concepts to provide recourse for tissue donors.²³ The merit of the property theory has been recognized; however, it has not been accepted by courts.²⁴

This paper identifies barriers to privacy tort actions and property theory, and demonstrates why *quasi-property* rights, which protect privacy regarding human remains and reproductive tissues, should be projected into the world of genetics/genomics.²⁵ The merit of *quasi-property* is explained as well as its limitations.²⁶

Background briefly describes the evolution of genetics and genomics and the distinctive characteristics of genetic/genomic research.²⁷ It describes why genetic/genomic information has been treated as a distinctive group of information.²⁸ *Argument* then delineates the developing concept of privacy, bridging from torts to the Constitution.²⁹ It overviews tissue donors' interest in genetic/genomic information and shows that the risk of injury is intensified

19. See McGuire & Beskow, *supra* note 7, at 367; Privacy and Progress, *supra* note 12, at 83; Jessica L. Roberts, *Progressive Genetic Ownership*, 93 NOTRE DAME L. REV. 1105, 1130-31, 1169 (2018). Genetic/genomic information includes any data or information that describes genetic/genomic structures or sequences about individuals. It includes raw data of DNA and RNA analysis, the measurements of molecular markers, clinical observations about conditions caused by gene/genome irregularities. See Genetic Information Nondiscrimination Act of 2008 ("GINA"), 42 U.S.C. § 2000ff(4)(A) (2012). See also 29 C.F.R. § 1635.3(c) (2014). Given the ability to re-identify test subjects, protectable genetic/genomic information should include information which is re-identifiable using current and future technologies.

20. Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 33-34 (Mark A. Rothstein ed. 1997).

21. Van Assche et al., *supra* note 14, at 75.

22. See, e.g., ALAN F. WESTIN, PRIVACY AND FREEDOM 158 (1967); Allen, *supra* note 20, at 33-34.

23. See Roberts, *supra* note 19, at 1105, 1107 (discussing problems of viewing genetic ownership through a neoclassical law and economics lens); Anita L. Allen, *Coercing Privacy*, 40 WM. & MARY L. REV. 723 (1999).

24. See *infra* Argument Section B; see also Sonia M. Suter, *Disentangling Privacy from Property: Toward a Deeper Understanding of Genetic Privacy*, 72 GEO. WASH. L. REV. 737, 746, 809 (2004).

25. The *quasi-property* right is recognized for human tissues. See *infra* Argument Section B.

26. See *infra* Argument Section B.

27. See *infra* Background.

28. See *id.*

29. See *infra* Argument Section A.

among vulnerable minority groups.³⁰ Classic *quasi-property*—the ability to control remains of relatives—is explained, as well as its applicability to genetic/genomic information.³¹ The application of *quasi-property* to hypotheticals shows that *quasi-property* captures the nexus of genetic/genomic information and tissue donors’ dignity and autonomy, offering a balanced resolution.³²

BACKGROUND: TOMORROW IS A MYSTERY

Genetic/genomic information is characterized by several features, including its multiplicity, identifiability, and commonality.³³ This part demonstrates that genetic/genomic information has unparalleled significance to privacy protection because of the foregoing characteristics.³⁴

A. History of “Disfavored” Citizens: Risk of Stigmatization

Human traits such as eye colors are inheritable.³⁵ Inheritance begins when a child receives half of each parent’s genes, including those which determine eye color.³⁶ Modern genetics evolved after centuries of pursuing the substance behind human inheritance.³⁷ Genetics has produced technological breakthroughs and answered previously unanswerable questions.³⁸

Ironically, modern genetics was more of a curse than blessing to people with certain conditions.³⁹ In the late nineteenth century, prominent scholars advanced the position that human behaviors are programmed by the gene.⁴⁰

30. See *infra* Argument Section B (discussing the basis of broad consent and its problems).

31. See *id.*

32. See *id.*

33. See discussion *infra* Background Sections B, C.

34. See *infra* Background Sections B-D.

35. See generally Gregor Mendel, *Experiments in Plant Hybridization*, 4 VERHANDLUNGEN DES NATURFORSCHENDEN VEREINES IN BRÜNN 3 (1866); Harrison R. Hunt, *Intelligence as a Mendelian Character: A Suggestion Concerning the Mode of Inheritance of Mental Ability*, 17 J. HEREDITY 53 (1926).

36. Garland E. Allen, *The Social and Economic Origins of Genetic Determinism: A Case History of the American Eugenics Movement, 1900-1940 and Its Lessons for Today*, 99 GENETICA 77 (1997); Roberts, *supra* note 19, at 1122; Christopher P. Austin, *Deoxyribonucleic Acid (DNA)*, NAT’L HUM. GENOME RES. INST., <https://www.genome.gov/genetics-glossary/Deoxyribonucleic-Acid> (last visited Jan. 31, 2021).

37. Each person’s body is made up of cells containing forty-six (46) chromosomes. The twenty-three (23) pairs of chromosomes are about 3 billion base pairs long and contain around 30,000 genes. Privacy and Progress, *supra* note 12, at 109-11; Austin, *supra* note 36.

38. Allen, *supra* note 20, at 40.

39. Scientific advancements do not always create happiness to mankind. Thomas H. Huxley, *Science and Culture*, in 2 THE NORTON ANTHOLOGY OF ENGLISH LITERATURE 1620 (3d ed. 1974).

40. Francis Galton, a statistician and a sociologist, defined eugenics as a branch of study “which deals with all influences that improve the inborn qualities of a race.” See Allen, *supra* note 36, at 78; See

Genetic determinists argued that social problems should be preventable by eliminating the succession of “undesirable” genes.⁴¹ Classic eugenics developed from genetic determinism and forced racial hygiene in Germany.⁴² Nazis sterilized groups of individuals under the 1934 German Act.⁴³ Fears of pseudoscience persist even today.⁴⁴

B. Multiplicity of Interest

While the term “genetic” may evoke deep-seated sentiments among certain groups of people, newly developed technologies are rendering it a purely technical term.⁴⁵ Beginning with Watson and Crick’s seminal discovery, research has explored structures no greater than a nanometer.⁴⁶ Biologists have studied delicately controlled molecular cascades to conclude that epigenetic modulations (changes external to genes) can cause genome-wide alterations and serious medical conditions.⁴⁷ Many of the new findings are commonly found among patients with similar conditions.⁴⁸ Illnesses that were thought to be inheritable have been re-categorized as multifactorial from “congenital.”⁴⁹

The speed of today’s analytics is thousands of times faster than the Human Genome Project’s.⁵⁰ Whole genome sequencing is reportedly completed in one day.⁵¹ At the same time, human genome researchers are generating a staggering volume of data.⁵² In favor of the improved analytical power, leading research institutions have consolidated their data to establish

also C. P. Blacker, “Eugenic” Experiments Conducted by the Nazis on Human Subjects, 44 *Eugenics Rev.* 9, 10 (1952).

41. Charles B. Davenport, *Crime, Heredity, and Environment*, 19 *J. HEREDITY* 307 (1928).

42. See Blacker, *supra* note 40, at 10 (stating that eugenics is a merciful creed and Nazi racist practices were different from eugenics); see Allen, *supra* note 36, at 77.

43. Eugenics was successful in the United States, Britain, and Germany. Allen, *supra* note 36, at 77, 85.

44. Allen, *supra* note 36, at 78.

45. The term “genetic” has been used to mean “inheritable” or “familial.” Roberts, *supra* note 19, at 1122.

46. DNA is the substance that is used as a code in each gene. Human genome contains two strings of (double-stranded) DNAs that are approximately three-billion base long. The itinerary of our life-long biological development is written as sequences of DNAs in genome. J. D. Watson & F. H. C. Crick, *Molecular Structure of Nucleic Acids*, 171 *NATURE* 737 (1953).

47. See Xinchun Wang et al., *High-resolution Genome-wide Functional Dissection of Transcriptional Regulatory Regions and Nucleotides in Human*, 9 *NATURE COMMS.* 5380 (2018).

48. *Cleft Lip and Cleft Palate*, MAYO CLINIC, <https://www.mayoclinic.org/diseases-conditions/cleft-palate/symptoms-causes/syc-20370985> (last visited Jan. 31, 2021).

49. See *supra* note 48; William A. Eimer et al., *Alzheimer’s Disease-Associated β -Amyloid Is Rapidly Seeded by Herpesviridae to Protect Against Brain Infection*, 99 *NEURON* 56 (2018).

50. The Human Genome Project was launched in 1990 to perform sequencing of the human genome. It took more than twelve years to complete the project. *The Human Genome Project*, NAT’L HUM. GENOME RES. INST., <https://www.genome.gov/human-genome-project> (last visited Jan. 31, 2021).

51. BRUCE ALBERTS ET AL., *MOLECULAR BIOLOGY OF THE CELL* 533-34 (4th ed. 2002).

52. McGuire & Beskow, *supra* note 7, at 366.

“biobanks” and have correlated genetic/genomic data with health information of research participants.⁵³

In addition to freely accessible biobanks, there are proprietary databases that charge a fee to access their information.⁵⁴ The market value of big genetic databases is estimated to reach as much as millions of dollars.⁵⁵

C. Identifiability and Commonality

Genetic/genomic materials are rarely disconnected from hosts.⁵⁶ DNA fingerprinting technology links a small amount of tissue left at a crime scene to a perpetrator as DNA fingerprints are analyzed and give a match in a database.⁵⁷ Thus, even when the name of a person is removed from a biological sample, DNA fingerprints buried in samples reveal the person’s identity.⁵⁸ In fact, a cheek swab usually contains enough DNA fingerprints to identify its source.⁵⁹ Only when a negligible quantity of DNA fingerprints exist or genetic/genomic information is too small to disclose the identity of its donor is such a sample or information de-identified.⁶⁰ Therefore, the anonymity of genetic/genomic data is rarely achievable.⁶¹

53. Vanderbilt University and Northwestern University have linked their biobanks to electronic health records to uncover genotype-phenotype associations. See Lori B. Andrews, *Harnessing the Benefits of Biobanks*, 33 J. L. MED. ETHICS, 22, 22-23 (2005); Catherine A. McCarty et al., *The eMERGE Network: A Consortium of Biorepositories Linked to Electronic Medical Records Data for Conducting Genomic Studies*, 4 BMC MED. GENOMICS 13 (2011).

54. Jorge L. Contreras, *The False Promise of Health Data Ownership*, 94 N.Y.U. L. REV. 624, 630 (2019).

55. See Contreras, *supra* note 54 (global health data valued at \$100 billion per year); Matthew Herper, *Surprise! With \$60 Million Genentech Deal, 23andMe Has a Business Plan*, FORBES, (Jan. 6, 2015, 9:58 AM), <https://www.forbes.com/sites/matthewherper/2015/01/06/surprise-with-60-million-gene-tech-deal-23andme-has-a-business-plan/#3913bcb2be9> (“The deal is the first of ten 23andMe says it has signed with large pharmaceutical and biotech companies.”); Joseph N. DiStefano, *Test Results: Glaxo Pays 23andMe \$300M, Will Use 4 Million Customers’ Genetic Data*, PHILA. INQUIRER (July 25, 2018), <https://www.inquirer.com/philly/blogs/inq-phillydeals/test-results-23andme-sells-4-million-customers-genetic-data-to-glaxo-for-300m-20180725.html>.

56. Van Assche et al., *supra* note 14, at 69.

57. See NAT’L RES. COUNCIL, COMM. ON DNA TECH. IN FORENSIC SCI., NAT’L ACADEMY OF SCI., *DNA TECHNOLOGY IN FORENSIC SCIENCE* 155 (1992); S. Panneerchelvam & M. N. Norazmi, *Forensic DNA Profiling and Database*, 10 MALAY. J. MED. SCI. 20 (2003).

58. Erika Check Hayden, *The Genome Hacker, Yaniv Erlich Shows How Research Participants Can Be Identified from ‘Anonymous’ DNA*, 497 NATURE 172 (May 09, 2013).

59. See Jessica G. Woo et al., *Quality Assessment of Buccal Versus Blood Genomic DNA Using the Affymetrix 500 K GeneChip*, 8 BMC GENETICS 79 (2007); see generally Chao-Tien Chang, *Bank on We the People: Why and How Public Engagement Is Relevant to Biobanking*, 25 MICH. TECH. L. REV. 239 (2019) (discussing de-identified biospecimens).

60. C. Heeney et al., *Assessing the Privacy Risks of Data Sharing in Genomics*, 14 PUB. HEALTH GENOMICS 17 (2010).

61. Harald Schmidt & Shawneequa Callier, *How Anonymous Is ‘Anonymous’? Some Suggestions Towards a Coherent Universal Coding System for Genetic Samples*, 38 J. MED. ETHICS 304 (2012).

Further, re-identifying a tissue donor is increasingly possible thanks to emerging investigative techniques.⁶² Advanced data analytics can help investigators discover the identity of a tissue donor or a tissue donor's family based on gathered data.⁶³ The identity of a donor is even consciously kept for the purpose of returning important test results to the donor.⁶⁴

Along with identity-revealing short DNA sequences, DNA sequences contain clues for a host's health status.⁶⁵ To address concerns for genetic prejudice, legislative bodies have enacted genetic/genomic-specific laws.⁶⁶ In terms of the DNA fingerprints, the DNA Analysis Backlog Elimination Act of 2000 ("the DNA Act"), further supported by The Debbie Smith DNA Backlog Grant Program, prohibits access except specifically allowed.⁶⁷

Professor Scherr wrote that "[i]nformation from DNA analysis can be intimate, personal, shared, predictive, and powerful."⁶⁸ Privacy concerns are underscored in genetic research because obtained information could suggest a person's serious health condition, or evidence that a person comes from a particular ethnic group.⁶⁹ It may also be used in making marriage decisions and childbearing choices.⁷⁰ The disclosure of these types of information affects the tissue donor's family relationships, life plans, and even social or economic status.⁷¹

62. *Id.* at 305.

63. Anonymized data can later be integrated with other data. PRIVACY AND PROGRESS, *supra* note 12, at 64.

64. The American College of Medical Genetics recommends using DNA genotyping tests to track the identity of the donor of the sample. Robert C. Green et al., *ACMG Recommendations for Reporting of Incidental Findings in Clinical Exome and Genome Sequencing*, 15 GENETICS IN MED. 565 (2017).

65. See Shoko Kawamoto, et al., *Expression Profiling by iAFLP: A PCR-Based Method for Genome-Wide Gene Expression Profiling*, 9 GENOME RES. 1305 (1999); Mark Schena, et al., *Parallel human genome analysis: microarray-based expression monitoring of 1000 genes*, 93 PROC. OF NAT'L ACAD. SCI. 10614 (1996); Dieter Holger, *Best DNA Testing Kits: Discover the Secrets Stored in Your Genes*, PCWORLD, <https://www.peworld.com/article/3317567/best-dna-kits.html> (last visited Jan. 31, 2021); PRIVACY AND PROGRESS, *supra* note 12, at 25.

66. See Mark A. Rothstein, *Health Privacy in the Electronic Age*, 28 J. LEGAL MED. 487, 495 (2007); Allen, *supra* note 23, at 724; PRIVACY AND PROGRESS, *supra* note 12, at 66-67.

67. DNA Analysis Backlog Elimination Act of 2000, Pub. L. No. 106-546, 114 Stat. 2726 (2000) (codified as amended at 42 U.S.C. § 14135, transferred to 34 U.S.C. § 40706); The Debbie Smith DNA Backlog Grant Program, 34 U.S.C. § 40701 (2019) (formerly cited as 42 U.S.C. § 14135).

68. Albert E. Scherr, *Genetic Privacy & the Fourth Amendment: Unregulated Surreptitious DNA Harvesting*, 47 GA. L. REV. 445, 492 (2013).

69. See *Schmerber v. California*, 384 U.S. 757, 767 (1966) (privacy protection under the Fourth Amendment); *Skinner v. Railway Labor Executive's Ass'n*, 489 U.S. 602, 617 (1989) ("analysis of urine, like that of blood, can reveal a host of private medical facts . . . including whether he or she is epileptic, pregnant, or diabetic"); Garrison, *supra* note 14, at 217.

70. Erik Lief, *DNA-Based Dating Using 'Attraction' Genes Attracts Questions*, AM. COUNCIL SCI. HEALTH (Feb. 3, 2018), <https://www.acsh.org/news/2018/02/03/dna-based-dating-using-attraction-genes-attracts-questions-12516>.

71. PRIVACY AND PROGRESS, *supra* note 12, at 24-25.

Also, genetic/genomic information includes elements shared with others.⁷² Around 99.9% of the human genome is identical.⁷³ The commonality is advantageous in that genetic/genomic information is generalizable and can pave a way to life-saving treatments for many.⁷⁴ The commonality explains why tissues are donated for genetic/genomic research.⁷⁵

However, the commonality may harm individual privacy.⁷⁶ Since a person's genetic abnormality can be shared amongst his or her kindreds, a test result may cause an unexpected issue to individuals biologically related to the tested person.⁷⁷ As seen in Senator Warren's DNA testing, the disclosure of one person's test result may cause disruption to another's public reputation and cultural and personal values, if the genetic/genomic similarity is expected to be high.⁷⁸

D. Summary

Overall, genetic/genomic information is a special class of information with remarkable characteristics: multiplicity, identifiability, and commonality.⁷⁹ Numerous tissue donations make up valuable genetic/genomic information.⁸⁰ The commonality is beneficial in biomedical research and development but is associated with privacy ripple effects.⁸¹

72. *Genetics vs. Genomics Fact Sheet*, NAT'L HUM. GENOME RSCH. PROJECT (Sept. 7, 2018), <https://www.genome.gov/about-genomics/fact-sheets/Genetics-vs-Genomics>.

73. *Id.*

74. *What is the Human Genome Project?*, NAT'L HUM. GENOME RES. PROJECT (October 28, 2018), <https://www.genome.gov/human-genome-project/What>.

75. Human genetic pool can be considered as semicommons property. See Henry E. Smith, *Semicommon Property Rights and Scattering in the Open Fields*, 29 J. LEGAL STUD. 131, 131-32 (2000); Ken Gatter, *Biobanks as a Tissue and Information Semicommons: Balancing Interests for Personalized Medicine, Tissue Donors and the Public Health*, 15 J. HEALTH CARE L. & POL'Y 303, 335-36 (2012).

76. Michelle Hibbert, *DNA Databanks: Law Enforcement's Greatest Surveillance Tool?*, 34 WAKE FOREST L. REV. 767, 782-84 (1999).

77. A child's DNA test can provide DNA evidence of the child's parent's crime. See Alice A. Noble, *DNA Fingerprinting and Civil Liberties*, 34 J.L. MED. & ETHICS 149, 150 (2006) (components shared among a kinship group or a small population); Hibbert, *supra* note 76, at 782-84 (describing an arrest of a family member of a suspect from a DNA sample); Gina Kolata & Heather Murphy, *The Golden State Killer Is Tracked Through a Thicket of DNA, and Experts Shudder*, N.Y. TIMES (Apr. 27, 2018), <https://www.nytimes.com/2018/04/27/health/dna-privacy-golden-state-killer-genealogy.html>.

78. Findings obtained from genetic/genomic studies are relevant to many whether results are good or bad. See *supra* notes 1-4 and accompanying text for a description of Senator Warren's DNA test incident.

79. See *infra* Background Sections B, C.

80. Panneerchelvam & Norazmi, *supra* note 57, at 20.

81. Hibbert, *supra* note 76, at 767, 791, 793-94 (DNA banks can be utilized to garner health and other information about the tested person, as well as his or her relatives); Mark A. Rothstein & Sandra Carnahan, *Legal and Policy Issues in Expanding the Scope of Law Enforcement DNA Data Banks*, 67 BROOKLYN L. REV. 127, 164 n.216 (2001).

Minority groups and patients with rare conditions are at higher risk of privacy invasion.⁸²

ARGUMENT: *QUASI-PROPERTY* RIGHT AS NON-COMMON PRIVACY INTEREST

After different approaches and mechanisms are overviewed, *Argument* shows that *quasi-property* rights must be considered to reinforce missed privacy protection for genetic/genomic information without overburdening important biomedical research.⁸³

A. *Privacy in Human Tissues and Biomedical Information*

1. *The Right to Privacy*

The right to privacy guarantees freedom to be left alone.⁸⁴ The concept of privacy dates back to Brandeis and Warren's paper that called attention to the media's encroachment upon privacy.⁸⁵ Brandeis and Warren found a copyright case in English literature,⁸⁶ and introduced the right of privacy into U.S. common law.⁸⁷

Later, the Supreme Court of Georgia concluded that every man is entitled to enjoy the right to privacy, whether within or outside of society.⁸⁸ The Georgia court's approach was followed by other courts.⁸⁹ The Supreme Court

82. NAT'L ACADS. OF SCIS., ENG'G, & MED., AN EXAMINATION OF EMERGING BIOETHICAL ISSUES IN BIOMEDICAL RESEARCH at 56 (2020) (highlighting the American Indian/Alaskan Native population's higher risk of identification and stigmatization).

83. See *infra* Argument Sections A, B, C, D, and E.

84. In the Restatement (Second) of Torts, the following classes of privacy invasions are described as judicially recognized: "(a) unreasonable intrusion upon the seclusion of another, . . . (b) appropriation of the other's name or likeness, . . . (c) unreasonable publicity given to the other's private life, . . . or (d) publicity that unreasonably places the other in a false light before the public." RESTATEMENT (SECOND) OF TORTS § 652A (1977); William L. Prosser, *Privacy*, 48 CAL. L. REV. 383, 389 (1960) (categories of privacy torts).

85. See Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193, 195-96 (1890); James H. Barron, *Warren and Brandeis, the Right to Privacy*, 4 HARV. L. REV. 193 (1890); *Demystifying a Landmark Citation*, 13 SUFFOLK UNIV. L. REV. 875, 883 (1979); Neil M. Richards & Daniel J. Solove, *Privacy's Other Path: Recovering the Law of Confidentiality*, 96 GEO. L.J. 123, 128-29 (2007).

86. Warren & Brandeis, *supra* note 85, at 208-09.

87. The right to privacy has been widely accepted in most states. See *Anderson v. Romero*, 72 F.3d 518, 521-22 (7th Cir. 1995); RESTATEMENT (SECOND) OF TORTS § 652A (1977); STUART M. SPEISER ET AL., 9 AMERICAN LAW OF TORTS § 30:1 (Monique C. M. Leahy ed., 2021); Harry Kalven, Jr., *Privacy in Tort Law—Were Warren and Brandeis Wrong?*, 31 L. & CONTEMP. PROBS. 326, 327-28 (1966); Andrew Jay McClurg, *Bringing Privacy Law Out of the Closet: A Tort Theory of Liability for Intrusions in Public Places*, 73 N.C. L. REV. 989, 999 (1995).

88. See *Pavesich v. New England Life Ins. Co.*, 50 S.E. 68, 70 (Ga. 1905); Warren & Brandeis, *supra* note 85, at 198 (Roman law provides a remedy for unjust violations of one's honor).

89. See *People ex rel. Gow v. Bingham*, 107 N.Y.S. 1011, 1014 (Sup. Ct. 1907) ("the right to preserve his person inviolate from attack by any other person"); *Rhodes v. Graham*, 37 S.W.2d 46, 47 (Ky.

of Indiana held that “[t]he [r]ight of [p]rivacy . . . [is] derived from natural law and guaranteed by both the Federal and State Constitutions. As between man and man it must be respected.”⁹⁰ Two layers of privacy have been developed: informational and decisional.⁹¹ Informational privacy prevents unwanted disclosure of another’s private facts and preserves his or her dignity.⁹² Decisional privacy guarantees one’s liberty to make important life decisions.⁹³

Among the causes of action that fall within informational privacy, intrusion upon seclusion provides the most relevant framework for the collection of genetic/genomic information and its use.⁹⁴ In the majority of jurisdictions, intrusion upon seclusion requires facts supporting the following elements: (1) intrusion, usually achieved by watching, spying, prying, overhearing, or other similar conduct;⁹⁵ (2) concerning the “solitude or seclusion of another or his [or her] private affairs . . . [; (3)] highly offensive to a reasonable person”; and (4) a defendant’s intentional act.⁹⁶ Another category, publication of private facts, has similar elements.⁹⁷ Whether a defendant’s intrusion is highly offensive depends upon circumstances: the “likelihood of serious harm to the victim[s],” the manner of intrusion, “the intruder’s motives,” and the existence of “countervailing interests.”⁹⁸

The identifiability of a privacy victim is located at the intersection of privacy law and privacy regulations.⁹⁹ The disclosure of identity is treated as an important fact to claims based on publication of private facts.¹⁰⁰ On the other hand, it is not settled whether the victim’s identity is essential in establishing an intrusion upon seclusion claim.¹⁰¹ When an employer’s

1931); *Eick v. Perk Dog Food Co.*, 106 N.E.2d 742, 743, 748 (Ill. App. Ct. 1952); *Pritchett v. Bd. of Comm’rs of Knox Cty.*, 85 N.E. 32, 35 (Ind. Ct. App. 1908).

90. *See Voelker v. Tyndall*, 75 N.E.2d 548, 549 (Ind. 1947).

91. *Whalen v. Roe*, 429 U.S. 589, 598-600 (1977). *See supra* note 84 (for four categories of privacy torts).

92. *See Whalen*, 429 U.S. at 598-600; Jay P. Kesan et al., *Information Privacy and Data Control in Cloud Computing: Consumers, Privacy Preferences, and Market Efficiency*, 70 WASH. & LEE L. REV. 341, 384-86 (2013).

93. Individuals are “left to shape [their] own life as [they] think[] best, do what [they] please[], go where [they] please[].” *Doe v. Bolton*, 410 U.S. 179, 213 (1973) (Douglas, J., concurring) (quoting *Kent v. Dulles*, 357 U.S. 116, 126 (1958)).

94. *See generally* RESTATEMENT (SECOND) OF TORTS § 652B (1977).

95. *Snakenberg v. Hartfoed Casualty Ins. Co.*, 299 S.C. 164, 171, 388 S.E.2d 2 (1989).

96. RESTATEMENT (SECOND) OF TORTS § 652B (1977).

97. RESTATEMENT (SECOND) OF TORTS § 652D (1977).

98. *Davis v. Facebook, Inc. (In re Facebook Inc. Internet Tracking Litig.)*, 956 F.3d 589, 606 (9th Cir. 2020).

99. *See WESTIN, supra* note 22, at 69 (“[T]he ability to move about anonymously”); Tom Gerety, *Redefining Privacy*, 12 HARV. C.R.-C.L. L. REV. 233, 282, 284, 288, 291 (1977).

100. *See Floa. Star v. B. J. F.*, 491 U.S. 524, 537 (1989); *Melvin v. Reid*, 297 P. 91, 93-94 (Cal. Dist. Ct. App. 1931) (finding privacy invasion by a filmmaker when the plaintiff’s true name was disclosed).

101. *In re Nickelodeon Consumer Privacy Litig.*, 827 F.3d 262, 293-295 (3d Cir. 2016).

access to employees' email communications is sought to be banned, the probability of identifying an employee is considered pertinent.¹⁰² Also, a sperm donor's attempt to ascertain his biological child may disrupt another's seclusion.¹⁰³ These examples indicate that when a subject's identity is easily ascertainable, the degree of privacy disruption is more significant.

Nevertheless, the expectation of privacy and the expectation of anonymity are two distinctive concepts.¹⁰⁴ The Third Circuit permitted a plaintiff's intrusion into seclusion claim without inquiring whether the defendant collected and disclosed information containing personal identifiers.¹⁰⁵ The Third Circuit's opinion supports the view that the victim's reasonable expectation of privacy, rather than the identifiability of the victim, is a key question.¹⁰⁶

Assuming a *prima facie* case of privacy invasion, a defendant may argue that the plaintiff's consent eliminates tort liability.¹⁰⁷ Since a plaintiff's consent to a defendant justifies the defendant's privacy invasion, the issue of consent is a key question for a privacy plaintiff.¹⁰⁸

The second type of privacy—decisional privacy—originates from Justice Cardozo's opinion that endorsed the right to control one's bodily integrity in medical procedures.¹⁰⁹ The respect for autonomy has developed into the mandate of informed consent, compelling a provider's disclosure of information before obtaining consent.¹¹⁰ Informed consent was established on the view that each individual has a different set of personal values and perspective, and the disclosure of important facts is necessary for an individual to make a choice.¹¹¹

102. George R. Lucas, Jr., *Privacy, Anonymity, and Cyber Security*, 5 AMSTERDAM L. F. 107, 109, 111, 113 (2013) (observing the problem of equating anonymity with privacy).

103. Lucy R. Dollens, *Artificial Insemination: Right of Privacy and the Difficulty in Maintaining Donor Anonymity*, 35 IND. L. REV. 213, 236-37 (2001).

104. Anonymity is indirectly protected by data protection law. Jeffrey M. Skopek, *Reasonable Expectations of Anonymity*, 101 VA. L. REV. 691, 717-18, 758 (2015).

105. *In re Nickelodeon Consumer Privacy Litig.*, 827 F.3d 262, 293-95 (3d Cir. 2016) (denying a Video Privacy Protection Act violation claim for lack of personally identifiable information and sustaining intrusion upon seclusion when an internet advertising company disregarded its promise not to collect personal information from children).

106. *Nickelodeon*, 827 F.3d at 292, 294. The presence of identity-revealing elements may not be strictly required in certain privacy torts. See *infra* Argument Section B.

107. Consent is a defense to intentional torts. RESTATEMENT (SECOND) OF TORTS § 892A (1979). See also 5 U.S.C. § 552a(b) (written consent); CHRISTINE RIEFA ET AL., 1 LAW OF THE INTERNET § 2.06 (2020).

108. RESTATEMENT (SECOND) OF TORTS § 892A (1979).

109. *Schloendorff v. Soc'y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914) ("Every human being of adult years and sound mind has a right to determine what shall be done with his own body.").

110. See *Salgo v. Leland Stanford Jr. Univ. Bd. of Trs.*, 317 P.2d 170, 181 (Cal. Dist. Ct. App. 1957); *Moore v. Regents of Univ. of Cal.*, 793 P.2d 479, 483 (Cal. 1990); RUTH R. FADEN & TOM L. BEAUCHAMP, A HISTORY AND THEORY OF INFORMED CONSENT 7 (1986).

111. See *In re Storar*, 420 N.E.2d 64, 70, 72 (N.Y. 1981); *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 271, 286-87 (1990) (confirming a right to refuse medical treatment) (citing Superintendent of

The Supreme Judicial Court of Massachusetts relied on the rights of privacy and informed consent to recognize substituted consent for withholding chemotherapy.¹¹² The principle of informed consent has encompassed non-therapeutic human research given that there can be a serious risk of bodily injury as well as harm to the personal values and beliefs of participants.¹¹³ The distinction of investigator-participant relationship from doctor-patient relationship is not dispositive to the duty of informed consent.¹¹⁴

In sum, the right to privacy guarantees one's freedom to live with dignity and autonomy.¹¹⁵ Informational privacy actions, such as claims based on invasion into seclusion, often fail to offer effective solutions.¹¹⁶ In contrast, decisional privacy has been playing a more important role.¹¹⁷ The informed consent claim by a research participant who suffered a serious adverse effect has been sustained.¹¹⁸

2. Constitutional Developments

The constitutional right of privacy primarily guarantees every individual's "possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law."¹¹⁹ This includes a person's bodily integrity, freedom to have a family and procreate, a right to abort, liberty to have an intimate relationship, and a right to personal dignity.¹²⁰ In the area of genetic privacy, the Supreme Court has indicated that unauthorized use of genetic/genomic information

Belchertown State Sch. v. Saikewicz, 370 N.E.2d 417, 424 (Mass. 1977)). See also FADEN & BEAUCHAMP, *supra* note 110, at 7; Douglas S. T. Green & C. Ronald MacKenzie, *Nuances of Informed Consent: The Paradigm of Regional Anesthesia*, 3 HOSP. SPECIAL SURGERY J. 115, 115 (2007).

112. The court reasoned that the value of human dignity extends to incompetent persons. *Saikewicz*, 370 N.E.2d at 419, 424, 427, 435.

113. See *Grimes v. Kennedy Krieger Inst., Inc.*, 782 A.2d 807, 812-13, 844 (Md. 2001) (duty to inform children's risk of irreversible injuries); *Whitlock v. Duke Univ.*, 637 F. Supp. 1463, 1471 (M.D.N.C. 1986) (the higher level of risk disclosure applicable to non-therapeutic experimentation); Valerie Gutmann Koch, *A Private Right of Action for Informed Consent in Research*, 45 SETON HALL L. REV. 173, 183 (2015) (recognizing the underdeveloped right of informed consent in research); Clarissa Allen et al., *Data Sharing, Biobanks and Informed Consent: A Research Paradox?*, 7 MCGILL J.L. & HEALTH 85, 105-06 (2013) (Canada's strict informed consent requirements and broad consent). But see *Wright v. Fred Hutchinson Cancer Research Center*, 269 F. Supp. 2d 1286, 1291, 1296 (W.D. Wash. 2002) (denying the informed consent cause of action).

114. *Moore*, 793 P.2d at 483.

115. *Saikewicz*, 370 N.E.2d at 424; FADEN & BEAUCHAMP, *supra* note 110, at 7.

116. See *supra* notes 99-106 and accompanying text.

117. See *supra* notes 109-110 and accompanying text.

118. *Grimes*, 782 A.2d at 812, 819, 824-26, 844, 858.

119. See *Union P. R. Co. v. Botsford*, 141 U.S. 250, 251-52 (1891).

120. *Rochin v. California*, 342 U.S. 165, 172 (1952); *Skinner v. Oklahoma ex rel. Williamson*, 316 U.S. 535, 541 (1942); *Whalen*, 429 U.S. at 598-600.; Radhika Rao, *Property, Privacy, and the Human Body*, 80 B.U. L. REV. 359, 360 n.2, 399 (2000) (explaining that the constitutional right of privacy is synonymous with personal autonomy).

constitutes a threat to a tissue owner's dignity under the Fourth Amendment.¹²¹

The Constitution guarantees one's freedom to have a family, engage in sexual conducts, and manage other reproductive matters.¹²² Under the Fourteenth Amendment, "liberty" should include so-called decisional privacy to embrace a person's freedom to use and control genetic/genomic information; as the use and control is indispensable to the person's seminal decisions in life and as vital as those aforementioned.¹²³ The second category of privacy, informational privacy, bolsters a person's right to control information.¹²⁴ Justice Brennan explained that an "individual's interest in avoiding disclosure of personal matters is an aspect of the right of privacy" protected by the Fourteenth Amendment.¹²⁵ The constitutional footings of informational privacy have been found in the First Amendment, the Third Amendment, the Fourth Amendment, and the Fifth Amendment.¹²⁶ Moreover, informational privacy supplements a person's decisional privacy in the matters involving "the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy."¹²⁷ The

121. See *Schmerber*, 384 U.S. at 767 (privacy protection under the Fourth Amendment); *Skinner*, 489 U.S. at 616-18. ("analysis of urine, [or] blood, can reveal a host of private medical facts about an [individual], including whether he or she is epileptic, pregnant, or diabetic."); *U.S. v. Navarro-Gonzalez*, No. 12-CR-158-A, 2013 U.S. Dist. LEXIS 99287, at *6 (W.D.N.Y. July 12, 2013) (quoting *Schmerber*, 384 U.S. at 767).

122. U.S. CONST. amend. XIV § 1. The Supreme Court has afforded protection for decisional privacy. See *Pierce v. Soc'y of Sisters*, 268 U.S. 510 (1925) (liberty to educate one's children); *Meyer v. Nebraska*, 262 U.S. 390 (1923) (liberty to learn foreign languages); *Skinner v. Oklahoma*, 316 U.S. 535 (1942) (right of procreation); *Griswold v. Connecticut*, 381 U.S. 479 (1965) (privacy of the marital relation); *Loving v. Virginia*, 388 U.S. 1 (1967) (right to marry); *Eisenstadt v. Baird*, 405 U.S. 438 (1972) (liberty to use contraception); *Roe v. Wade*, 410 U.S. 113 (1973) (abortion); *Zablocki v. Redhail*, 434 U.S. 374 (1978) (a right to marry); *Lawrence v. Texas*, 539 U.S. 558, 574 (2003) (homosexual conducts); *U.S. v. Windsor*, 570 U.S. 744 (2013) (same sex marriage); *Obergefell v. Hodges*, 576 U.S. 644 (2015) (same sex marriage).

123. See *Vitek v. Jones*, 445 U.S. 480, 494, (1980) (liberty to resist transfer to mental hospital and mandatory behavior modification treatment); *Parham v. J.R.*, 442 U.S. 584, 600, (1979) (liberty interest in not being confined unnecessarily for medical treatment); *Cruzan*, 497 U.S. at 277-78 (1990) (confirming the right to refuse medical treatment); LAURENCE H. TRIBE, *AMERICAN CONSTITUTIONAL LAW* § 15-11, at 1365 (2d ed. 1988) (the constitutional privacy right in addition to common law right to refuse medical treatment).

124. *Whalen*, 429 U.S. at 598-99.

125. "Personal matters" are inclusive of the person's reputation and dignity, such as criminal record. See *Whalen*, 429 U.S. 593, 606 (Brennan, J., concurring) (a statute requiring disclosure of the identity of a person seeking prescription of controlled substances); *U.S. Dep't of Justice v. Reporters Comm. for Freedom of Press* 489 U.S. 749, 778-80 (1989).

126. See, e.g., *Katz v. U.S.*, 389 U.S. 347, 350-51 (1967) (listing constitutional provisions for privacy) (quoting *Nat'l Ass'n for Advancement of Colored People v. Alabama*, 357 U.S. 449, 462 (1958); *Tehan v. Shott*, 382 U.S. 406, 416 (1966)).

127. One's liberty to control information related to personal matters makes whole "the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life." *Planned Parenthood v. Casey*, 505 U.S. 833, 851 (1992).

two components of privacy merge and guarantee a right of genetic/genomic integrity.

3. *The Right to Privacy in Genetic/Genomic Research*

Do participants in genetic/genomic studies have a tort claim arising from unconsented use of genetic/genomic information? As noted earlier, genetic/genomic information is a special class of information: the heightened risk of stigmatization against minority groups; the identifiability of subjects; and genetic/genomic commonality.¹²⁸ In consideration of these features, many of us would think that unauthorized use of genetic/genomic data should constitute an intrusion upon seclusion.¹²⁹

More unclear is whether a consent form, signed by a participant, can successfully protect researchers. Even with evidence of consent, researchers may still be found liable because consent is only effective within certain limits and conditions that accompany it.¹³⁰ Anything that goes beyond what consent was specifically given for, may create a cause of action for future disputes.¹³¹ Furthermore, the validity of consent is also contestable.¹³² A participant can argue that the researchers misled them or failed to inform them of the serious risks involved in the study.

Informed consent claims protect research participants from unconsented disclosure of exceptionally important information both informational privacy and decisional privacy derived.¹³³ As the Havasupai Tribe experienced, what can be gleaned from a sample is shocking to those participants who have never been informed on the privacy implication of invasive study findings.¹³⁴

128. Unique characteristics of genetic/genomic information. See *infra* Background.

129. See *supra* notes 94-98 and accompanying texts. (1) A genetic analysis and use of results can constitute intrusion because it is equivalent to prying into someone's sensitive health information. (2) It also concerns the solitude or seclusion of another, or his or her private affairs, when obtained data contains or shows a test subject's identity and the analysis reveals matters usually kept secret (a person's gene/genome constitute). (3) Unauthorized use of genetic information is often highly offensive to a reasonable person, depending on the nature, manner, and purpose of the use and analysis. (4) Use and analysis of data is usually intentional.

130. *Moore v. Regents of Univ. of Cal.*, 51 Cal. 3d 120, 124-125 (1990).

131. See RESTATEMENT (SECOND) OF TORTS §§ 892, 892A, 892B (1977); *Schneckloth v. Bustamonte*, 412 U.S. 218, 235, 248 (1973) (voluntariness of consent).

132. *Grimes v. Kennedy Krieger Inst., Inc.*, 366 Md. 29, 98 (2001).

133. *Whalen*, 429 U.S. at 598-600.

134. See *Participating in Genomics Research*, NAT'L HUMAN GENOME RESEARCH INST. (Jan. 10, 2018) [hereinafter *Participating*], <https://www.genome.gov/about-genomics/policy-issues/Human-Subjects-Research-in-Genomics/Participating-in-Research>; Polakit Teekakirikul et al., *Inherited cardiomyopathies: molecular genetics and clinical genetic testing in the postgenomic era* 15, THE JOURNAL OF MOLECULAR GENETICS 158, 166 (2013); Jasmin Wertz et al., *Genetics and Crime: Integrating New Genomic Discoveries Into Psychological Research About Antisocial Behavior*, 29 PSYCHOLOGICAL SCIENCE 791 (2018); Holger, *supra* note 65.

The requirement of informed consent is designed to prevent privacy victims' suffering.¹³⁵

Fact finders should consider both informational and decisional privacy harms if biological samples obtained under broad consent are used for intrusive studies when participants were not fully informed. Provided that participants were informed of the possibility of future genetic research, "broad" consent to genetic studies is nominally present.¹³⁶ Nevertheless, with regard to informational privacy, issues related to the scope and validity of consent remain; additional genetic/genomic studies may have a distinct impact upon participants' enjoyment of intimate matters because their dignity rests upon being fully informed.¹³⁷ This would apply equally to decisional privacy when participants are deprived of information to truly understand what is at stake.¹³⁸ In view of the significance of the risk of stigmatization and the absence of appreciation of such significance by average participants, consent may not be found when it is difficult to anticipate the intrusiveness of additional studies at the moment broad consent is given.¹³⁹

In addition to privacy tort claims and informed consent claims, constitutional remedies may be available when the government is involved in the unauthorized use or collection of genetic/genomic data.¹⁴⁰ First, freedom to access and use a critical piece of one's genetic information presents life-defining choices in connection with decisional privacy; genetic/genomic testing would be essential to the parents who lost a child to an incurable condition caused by a genetic mutation.¹⁴¹ The parents usually decide to receive a genetic examination to understand the probability of disease succession to prevent another loss of a child.¹⁴² Genetic/genomic testing provides a scientific evaluation and assists family planning and management and prevention of serious conditions.¹⁴³ Because of its centrality to the

135. *Moore*, 51 Cal. 3d at 143-44, 147.

136. Christine Grady et al., *Broad Consent For Research With Biological Samples: Workshop Conclusions*, 15(9) AM. J. BIOETH. 34, 38 (2015).

137. *Participating*, *supra* note 134; *Casey*, 505 U.S. at 851.

138. National Human Genome Research Institute considers that participants' primary objective to is altruistic and the Common Rule and other regulations will protect privacy. *Participating*, *supra* note 134 ("The main reason to participate is to advance science, so make sure you know what the study is designed to investigate and that it's something you want to help support.").

139. *Norman-Bloodsaw v. Lawrence Berkeley Lab.*, 135 F.3d 1260, 1268-70 (9th Cir. 1998) ("One can think of few subject areas more personal and more likely to implicate privacy interests than that of one's health or genetic make-up.").

140. See *Katz v. United States*, 389 U.S. 347 (1967); *Maryland v. King*, 569 U.S. 435, 464 (2013); Phillip B. Kurland, *The private I*, 69, No. 1 UNIVERSITY OF CHICAGO MAGAZINE 7, 8 (1976).

141. Beth A. Pletcher et al., *Indications for genetic referral: a guide for healthcare providers*, in 9 GENETICS IN MEDICINE, 385-89 (2007) (listing conditions indicated for genetic consultation and further testing).

142. See PRIVACY AND PROGRESS, *supra* note 12, at 22.

143. See PRIVACY AND PROGRESS, *supra* note 12, at 114; Pletcher, *supra* note 141.

enjoyment of life, freedom to utilize genetic testing should lie within the sanctuary of the Fourteenth Amendment.¹⁴⁴

Similarly, the Constitution should also guarantee the liberty to avoid unconsented genetic/genomic testing of sensitive matters if that the testing is incompatible with one's personal values and sense of self.¹⁴⁵ Informational privacy provides constitutional safeguards against the misuse of genetic/genomic information.¹⁴⁶ While the most common scenario is the application of DNA fingerprinting in criminal investigations, informational privacy protection is not limited to such use because of the nexus between what is disclosed from the analysis of a person's DNA and the possibility of mistreatment against groups with certain backgrounds.¹⁴⁷ The magnitude of traceable information by authorities is incomparable to other types of data, as is the gravity of the privacy injury that follows.¹⁴⁸ For example, a number of states formerly enforced compulsory sterilization against incarcerated people and patients with mental conditions.¹⁴⁹ The constitutional right of privacy is opening a new pathway against a real menace to our genetic integrity.¹⁵⁰

According to *Navarro-Gonzalez*, "the taking of buccal swabs from the inside of the defendant's mouth is properly viewed as implicating his dignity interests."¹⁵¹ With regard to the autonomy and dignity of research participants, opinions indicate that research participants and patients may claim a constitutional violation based on deceptive concealment of foreseeable risks to study participation, which is an issue separate from the

144. *See Whalen*, 429 U.S. at 606-07 (Brennan, J., concurring).

145. *Cruzan* indicates that courts generally consider the invasiveness of procedure as a factor to overcome state interest, but "the preservation of life, the protection of the interests of innocent third parties, the prevention of suicide, and the maintenance of the ethical integrity of the medical profession" support state interest. *Cruzan*, 497 U.S. at 271. The invasiveness inquiry should include injury to genetic integrity since one's genetic code may be inseparable from a person's personal values. *Supra* notes 3, 4, 13 and accompanying texts.

146. *Katz*, 389 U.S. at 350 (listing constitutional provisions for privacy) (quoting *NAACP*, 357 U.S. at 462; *Tehan*, 382 U.S. at 416).

147. *U.S. v. Navarro-Gonzalez*, No. 12-CR-158-A, 2013 U.S. Dist. LEXIS 99287, at *6-7 (W.D.N.Y. July 12, 2013) (viewing the DNA sample as implicating dignity interests of a tissue donor).

148. Genetic determinism and genetic discrimination persist until today. *See infra* Background Section A.

149. *People v. Barrett*, 54 Cal. 4th 1081, 1121-25 (2012) (Liu, J., concurring and dissenting) (history of eugenics in the United States).

150. Kurland, *supra* note 140, at 7-8.

151. *See Navarro-Gonzalez*, No. 12-CR-158-A, 2013 U.S. Dist. LEXIS 99287, at *6. In contrast, the standardized buccal swab collection and the registry of junk DNA segments at CODIS (criminal database) from those charged with a violent crime was held not sensitive enough to affect the suspect's dignity. *Maryland v. King*, 569 U.S. 435, 447-48, 463, 465 (2013) (Reasoning that (a) minor physical invasion, (b) no more than the identity-related analysis, (c) non-discretionary standard, (d) decreased privacy expectation due to the presence of probable cause for a serious crime). *But see King*, 569 U.S. at 466 (Scalia, J., dissenting) (noting the possibility of finding incriminating evidence through the identification process).

common law right to informed consent.¹⁵² Thus, a participant should be able to seek a remedy for a privacy invasion and potentially for a constitutional violation.

In response, study organizers and involved researchers may consider making the following arguments. First, they may submit an argument that a study was conducted based on an enormous number of samples for the purpose of scientific discovery; therefore, it would not be a “highly offensive” invasion.¹⁵³ As previously described, genetic/genomic research is simply carried out on multiple de-individualized samples whose donors’ privacy should not be affected.¹⁵⁴ Samples or extracted data are repeatedly used for different studies.¹⁵⁵ Thus, study findings are not expected to be ominous to a particular individual.¹⁵⁶ However, in the ASU Incident, the researchers conducted an undisclosed inbreeding study and an immigration study, which could have ruined the tribe’s sense of self and fractured the tribe’s solidarity.¹⁵⁷

Secondly, researchers may contend that there is no privacy invasion on the ground that used samples and data are coded (de-identified).¹⁵⁸ The identifiability of a tissue donor alone is likely not determinative to the outcome, as previously discussed.¹⁵⁹ However, it is possible that the plaintiff’s identifiability may be considered as a mitigating factor in certain circumstances.¹⁶⁰

Third, there are unresolved issues concerning the multiplicity of right holders and the interdependence of privacy interests.¹⁶¹ The multiplicity of interest may confound what remedy is available to a plaintiff. Even when a plaintiff wishes to gain control over his or her genetic/genomic information,

152. See *Heinrich v. Sweet*, 62 F. Supp. 2d 282, 313 (Mass. 1999) (radiation experiments known to have no therapeutic value); *Stadt v. Univ. of Rochester*, 921 F. Supp. 1023, 1025 (W.D.N.Y. 1996) (injection of plutonium under the pretense of treatment); *In re Cincinnati Radiation Litig.*, 874 F. Supp. 796, 812 (S.D. Ohio 1995) (the radiation as a military experiment). *But see* *Wright v. Fred Hutchinson Cancer Research Ctr.*, 269 F. Supp. 2d 1286, 1295-96 (W.D. Wash. 2002) (denying the violation of the Civil Rights Act claim).

153. *Davis v. Facebook, Inc.*, 956 F.3d 589, 606 (9th Cir. 2020).

154. *Participating*, *supra* note 134.

155. See *supra* Background Section B.

156. *Participating*, *supra* note 134.

157. See *supra* Introduction.

158. See *infra* note 214 and accompanying texts about the ASU’s use of coded samples, which the researchers considered would resolve privacy issues.

159. See *supra* notes 102-106 and accompanying texts.

160. For example, when a study is conducted on diverse demographics by multiple institutions.

161. See *supra* Background Sections B, C for the discussion of the multiplicity, the identifiability, and the commonality.

the justification for granting exclusive control over the information is widely debated.¹⁶²

The discussions in Section B will illustrate why there are multiple measures and different approaches that work in combination, and why *quasi-property* is necessary for individuals whose privacy has been harmed in genetic/genomic research.¹⁶³

B. Enhancement of Privacy Rights

Technological advancements have not only created the law of informational privacy as Warren and Brandeis had proposed, but they have also anchored genetic/genomic information to a multifaceted right of privacy.¹⁶⁴ The following paragraphs overview self-regulatory efforts and laws that have been put into practice and demonstrate that *quasi-property* is the optimal modality to shield tissue donors' genetic/genomic privacy.¹⁶⁵

1. Informed Consent and Broad Consent in Genetic/Genomic Research

U.S. legislatures have not enacted laws which permit privacy victims to seek information from or effective relief against infringing entities.¹⁶⁶ Enhanced privacy protection has been viewed negatively because a single donor's autonomy will limit other stakeholders' important interest in research.¹⁶⁷ Out of concern that "atomistic concept of autonomy" would undermine medical developments, informed consent has been second to scientific research.¹⁶⁸

In federally funded research involving human subjects, the Federal Policy for the Protection of Human Subjects Research (Common Rule) provides for informed consent.¹⁶⁹ The process of informed consent was designed to

162. To litigants who seek return of genetic information or those who seek return of study results, typical privacy actions do not render an effective remedy. See *infra* Section B for cases where the court denied relief requested by plaintiffs.

163. See *infra* Section B.

164. See *supra* notes 85-88 and accompanying texts for the development of informational privacy; Allen, *supra* note 20, at 34.

165. See *infra* Section B(1)-(7).

166. Generally, see *supra* Section A.3. and *infra* B.2. See also PRIVACY AND PROGRESS, *supra* note 12, at 65 ("these [foreign] laws differ from U.S. law, which is focused on prohibiting discrimination resulting from disclosure of genetic information rather than ensuring privacy of genetic information); Grady et al., *supra* note 136.

167. Barbara Evans, *Power to the People: Data Citizens in the Age of Precision Medicine*, 19 VAND. J. ENT. & TECH. L. 243, 258-259 (2016).

168. Evans, *supra* note 167 at 244-47; see also Erik Christensen, *Biobanks and Our Common Good*, in THE ETHICS OF RESEARCH BIOBANKING 101 (Jan Helge Solbakk et al., eds., 2009).

169. 42 U.S.C. § 241(d)(4) (2018). Because a right of informed consent is held to exist at common law, the statute is codification of the right at common law to some extent. See *Cruzan*, 497 U.S. at 271.

augment tissue donors' decisional privacy when a covered entity collects subject-identifiable information.¹⁷⁰ The informed consent requirement under the Common Rule does not guarantee flawless privacy protection.¹⁷¹

As commonly known, there are exceptions to the informed consent requirement: de-identified data; a participant who has given broad consent; and research that involves only minimal risk.¹⁷² According to the Advanced Notice of Proposed Rulemaking by the Department of Health and Human Services Office of Human Research Protections, samples may be used in subsequent studies as long as a participant signs a standard consent form.¹⁷³ The broad consent exception was introduced to further genetic/genomic research because time and costs to obtain informed consent would be prohibitive in large-scale genetic research.¹⁷⁴ Broad consent has been supported by a panel of bioethics experts,¹⁷⁵ and several studies reported that broad consent provides sufficient privacy protection.¹⁷⁶

Conversely, other studies indicated that broad consent may curtail participants' autonomy.¹⁷⁷ One study showed that a significant minority of participants desired to be informed of the process and have tighter control over their tissues.¹⁷⁸ In another study, only seventy-eight percent (78%) of the surveyed respondents indicated that they would agree to the use of their tissues for additional purposes in the future.¹⁷⁹ Further, significantly fewer African American respondents answered that they would give consent to

170. *Moore*, 51 Cal. 3d at 124-25, 139-40.

171. Grady et al., *supra* note 136, at 8.

172. 45 C.F.R. §§ 46.104(d), 46.116(d) (2018). The rule amended in 2017 greatly streamlined informed consent processes for genetic/genomic research. Key information needs to be provided to participants, such as risks and benefits of the study enrollment. See *Revised Common Rule*, U.S. DEP'T OF HUMAN HEALTH AND SCI., <https://www.hhs.gov/ohrp/regulations-and-policy/regulations/finalized-revisions-common-rule/index.html> (last visited Jan. 31, 2021).

173. See PRIVACY AND PROGRESS, *supra* note 12, at 91; Grady et al., *supra* note 136, at 2.

174. Human Subjects Research Protections: Enhancing Protections for Research Subjects and Reducing Burden, Delay, and Ambiguity for Investigators, 76 Fed. Reg. 44,512, 44514-44516, 44523-44524 (proposed Jul. 25, 2011). Another reason for providing an exception is the involvement of negligible physical risks to donors and the existence of other regulations to protect privacy. 76 Fed. Reg. 44,512.

175. Jonathan S. Miller, *Can I Call You Back? A Sustained Interaction with Biospecimen Donors to Facilitate Advances in Research*, 22 RICH. J.L. & TECH. 1, 15, 17 (2015).

176. Grady et al., *supra* note 136, at 4-5 ("the majority of . . . their willingness to donate specimens is not affected by the specific details of the future research, such as the disease being studied, the technology used . . . the study target (genes or white cells), or the product (treatment or prevention).").

177. Asa Kettis-Lindblad et al., *Genetic research and donation of tissue samples to biobanks. What do potential sample donors in the Swedish general public think?*, EUR. J PUB. HEALTH, 2006 Aug, at 437; Briana Mezuk et al., *Participant Characteristics That Influence Consent for Genetic Research in a Population-Based Survey: The Baltimore Epidemiologic Catchment Area Follow-Up*, 11 CMTY. GENETICS 171, 176-77 (2008); Christian M. Simon et al., *Active Choice But Not Too Active: Public Perspectives on Biobank Consent Models*, 13 GENETICS IN MED. 821, 825, 828 (2011).

178. Simon et al., *supra* note 177, at 825, 828 (25-32% of respondents preferred study-specific opt in consent).

179. Kettis-Lindblad et al., *supra* note 177, at 437.

donate a blood sample.¹⁸⁰ A Nigerian study also found that low-income earners were worried about the use of their biospecimens by foreign researchers.¹⁸¹ Clearly, there are different levels of concern regarding the use of biological samples, and individuals have their own preferred mode of participation in genetic/genomic research.¹⁸²

In addition to the foregoing observations that cast doubt on the broad consent exception, there is a theoretical weakness for circumnavigating informed consent with broad consent.¹⁸³ Informed consent requires sharing supplementary information with participants when any change in the circumstances renders previous information inadequate.¹⁸⁴ In broad consent, neither consent givers nor consent takers know exactly what study data will be used for in the future.¹⁸⁵ Without knowing details of future studies, the participant has not given real “informed” consent to them.¹⁸⁶ The substitution of specific consent with broad consent can eviscerate informed consent. Individuals with certain distinctive characteristics, or minorities, are more likely to be victimized as a result of a missed opportunity to consent.¹⁸⁷

In the ASU Incident, researchers omitted full disclosure and proceeded with intrusive genetic research that was arguably compliant with the Common Rule.¹⁸⁸ The current exceptions to the informed consent requirement become a loophole to scaled-up genetic research, particularly when a group of powerless people are selected as a study population.¹⁸⁹

The presence of consent, therefore, cannot eliminate tort liability.¹⁹⁰ The Court of Appeals of Maryland held that researchers cannot completely

180. Mezuk et al., *supra* note 177, at 173.

181. Michael A. Igbe & Clement A. Adebamowo, *Qualitative study of knowledge and attitudes to biobanking among lay persons in Nigeria*, 13 BMC MED ETHICS 1 (2012).

182. *Id.* at 1, 8.

183. Risks related to broad consent appear to be not uniform, and some participants are affected more than others. Peter A. Chow-White & Troy Duster, *Do Health and Forensic DNA Databases Increase Racial Disparities?*, PLOS MED. 2011 8(10), at e1001100.

184. Researchers must inform participants of any adverse effects that are later discovered, for example. FADEN & BEAUCHAMP, *supra* note 110, at 7-8.

185. See 45 C.F.R. §§ 46.104(d), 46.116(d), (2018); Catherine Heeney & Michael Parker, *Ethics and The Governance of Biobanks*, in GOVERNING BIOBANKS: UNDERSTANDING THE INTERPLAY BETWEEN LAW AND PRACTICE 290-91 (Michael Parker ed., 2012).

186. The informed consent must include “. . . a description of the procedures to be followed, and identification of any procedures which are experimental . . .” and “a description of any reasonably foreseeable risks or discomforts to the subject.” 45 C.F.R. § 46.116(a) (2018). In broad consent, it is not possible to describe the procedures and foreseeable risks that future studies will entail with regards to participants’ privacy.

187. See JESSICA W. BERG ET AL., INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE 258-59 (2d ed. 2001); Evans, *supra* note 167, at 258-59 (explaining the problems of waiver of consent in genetic research).

188. For pertinent discussions, see *supra* Argument Section C; Sterling, *supra* note 14, at 113.

189. Suzanne M. Rivera, *Modernizing Research Regulations Is Not Enough: It’s Time to Think Outside the Regulatory Box*, 17 AM. J. BIOETHICS 1 2017 (7), at 1.

190. *Grimes*, 366 Md. at 99.

immunize themselves by nominally obtaining consent, especially when the information given to tested individuals, or their guardians, is incomplete in a material aspect.¹⁹¹ In addition, even when a patient gave broad consent, the patient's claim for informed consent was not dismissed if an unhealed hole developed from a surgery, which the patient claimed the surgeon was responsible for.¹⁹²

Accordingly, broad consent does not ensure everyone's privacy. The risks associated with invasive genetic/genomic analysis compel us to follow an individualistic approach. Minority participants must not be neglected, even if it is "atomistic."¹⁹³

2. Statutory Safeguards for Genetic/Genomic Privacy

The danger of discrimination against certain patient groups and the reported misuse of genetic data have paved the way to stricter regulations on the use of genetic information.¹⁹⁴ The Genetic Information Nondiscrimination Act (GINA) of 2008 is a federal statute that protects genetic/genomic privacy.¹⁹⁵ GINA prohibits employment discrimination based on genetic compositions and medical histories suggestive of genetic aberrancies.¹⁹⁶ The DNA Act governs the collection and use of genetic/genomic information—DNA fingerprinting—in criminal investigations.¹⁹⁷ GINA and the DNA Act strengthen genetic/genomic privacy in two critical settings.¹⁹⁸ Neither GINA nor the DNA Act, however, realizes a tissue donors' active control over genetic/genomic information or provides comprehensive regulations.¹⁹⁹ The Health Insurance Portability and Accountability Act (HIPAA) protects medical information, but HIPAA does

191. *Id.* at 98.

192. *Anderson v. Jones*, 606 A.2d 185, 187-88 (D.C. 1992).

193. Evans, *supra* note 167, at 244-47.

194. Amanda Tessmer, *Pharmacogenomics and the Genetic Information Nondiscrimination Act of 2008: Legislation Limitations and Its Impact on Pgx Research and Clinical Opportunity*, 3 ST. LOUIS U.J. HEALTH L. & POL'Y 153, 172 (2009).

195. Amanda Tessmer, *Pharmacogenomics and the Genetic Information Nondiscrimination Act of 2008: Legislation Limitations and Its Impact on Pgx Research and Clinical Opportunity*, 3 ST. LOUIS U.J. HEALTH L. & POL'Y 153, 172 (2009).

196. *Id.* at 172.

197. Pub. L. No. 106-546 (codified as amended in scattered sections of 10 USC, in part at 18 USC § 3563 and former 42 USC §§ 14132, 14135a, 14135e).

198. Sejin Ahn, *Whose Genome Is It Anyway?: Re-identification and Privacy Protection in Public and Participatory Genomics*, 52 SAN DIEGO L. REV. 751, 772-73 (2015) (observing laws and regulations regarding genomic privacy lagging behind the speed of development of the technology).

199. Hibbert, *supra* note 76 at 819.

not add an extra layer of protection for genetic/genomic information.²⁰⁰ GINA and the DNA Act provide a floor for genetic privacy protection.²⁰¹

There are a few state laws that aim to protect privacy in general. These laws may restrict use and processing of genetic data by certain entities.²⁰²

3. Protection Outside Privacy

Several legal fabrics have offered relief for participants who have suffered damages in genetic/genomic research.²⁰³ Fiduciary duty, which governs medical providers' obligation to promote interest of a patient, is one option.²⁰⁴ Other approaches include the partnership analogy and the application of public trust.²⁰⁵ These theories offer a helpful guidepost in certain circumstances, but their scopes are limited because interactions between researchers and participants do not always amount to a formation of a joint enterprise or a trust.²⁰⁶

To the extent that genetic/genomic information can be seen as "common good," the approach that encourages participation of the general public is supportable.²⁰⁷ Further, the engagement of a whole community that participants belong to can augment mutual understanding between researchers and participating community members.²⁰⁸

200. Health Insurance Portability and Accountability Act (HIPAA) of 1996, § 1173(d), Pub. L. No. 104-191 (codified as 42 U.S.C. § 1320d-2 (2018)). The protected health information (PHI) is individually identifiable information that is "transmitted by" or "maintained in electronic media" or other forms of media. HIPAA requires the confidentiality, integrity, and availability of all e-PHI when providers create, receive, maintain or transmit PHI. See 42 U.S.C. § 1320d-2.; 45 C.F.R. § 160.103 (2018).

201. *Supra* note 194; Pub. L. No. 106-546.

202. See, e.g., CONSUMER DATA PROTECTION ACT OF 2021, VA. CODE ANN. § 59.1-578 (West 2021) (requiring consent to processing of sensitive data such as genetic or biometric data); PRIVACY LAWS, STATE OF CAL., <https://oag.ca.gov/privacy/privacy-laws> (last visited Nov. 14, 2021).

203. *Vodopest v. MacGregor*, 913 P.2d 779, 788 (Wash. 1996); Anna B. Laakmann, *When Should Physicians Be Liable for Innovation?*, 36 CARDOZO L. REV. 913, 954 (2015); Karine Morin et al., *Managing Conflicts of Interest in the Conduct of Clinical Trials*, 287 JAMA 78, 80-82 (2002); Angela Holder, *Do Researchers and Subjects Have a Fiduciary Relationship?* 4 IRB 6 (1982).

204. One problem of this approach is the doctor-patient relationship requirement. See *Vodopest*, 913 P.2d at 788; Anna B. Laakmann, *When Should Physicians Be Liable for Innovation?*, 36 CARDOZO L. REV. 913, 954 (2015); Morin et al., *supra* note 203, at 80-82; Holder, *supra* note 203.

205. See *Greenberg v. Miami Child. Hosp. Rsch. Inst., Inc.*, 264 F. Supp. 2d 1064, 1072-73, 175 (S.D. Fla. 2003) (joint venture); JESSICA W. BERG ET AL., *INFORMED CONSENT: LEGAL THEORY AND CLINICAL PRACTICE* 258-59 (2d ed. 2001) (citing PAUL RAMSEY, *THE PATIENT AS PERSON* (Yale University Press 1977), 5-6, as the framework of partnership); NAT'L ACAD. OF SCIENCES, ENG'G, AND MED., *RETURNING INDIVIDUAL RESEARCH RESULTS TO PARTICIPANTS: GUIDANCE FOR A NEW RESEARCH PARADIGM* 245 (Jeffrey R. Botkin et al. eds., 2018) (public trust).

206. See, e.g., E. Haavi Morreim, *Medical Research Litigation and Malpractice Tort Doctrines: Courts on a Learning Curve*, 4 HOUS. J. HEALTH L. & POL'Y 1, 48 (2003) (denying a fiduciary duty in biomedical research).

207. Public engagement or consultation may not substitute informed consent from individuals. See Christensen, *supra* note 168, at 103; Barbara Prainsack, *Research Populations: Biobanks in Israel*, 26 NEW GENETICS AND SOC. 85, 97 (2007).

208. Chang, *supra* note 59, at 239 (examples of community engagement and public consultation).

In contrast to these frameworks, the property theory introduces individualistic, capitalistic perspectives.²⁰⁹ The theory vests individual tissue donors with an ownership interest in tissues and genetic/genomic information taken from their bodies.²¹⁰ Under this theory, tissue donors may seek one or more of the following: recovery of tissues and data; prohibition against use of tissues and data; and a market value for use of tissues and data.²¹¹

In seeking control of extracted genetic/genomic information, aggrieved tissue donors have relied on “ownership” interest in removed tissues, without specifically stating they owned genetic/genomic information.²¹² The first hurdle to their claims, and to the property theory, is the common law antipathy against ownership interest in human bodies.²¹³ Arguments based on the property theory have mostly failed.²¹⁴ Rejecting a plaintiff’s assertion that a doctor had converted his spleen tissues, California’s highest court concluded that a patient is not an owner of tissues removed from a body.²¹⁵ The court reasoned that the law of property should not apply to human tissues given that freedom to dispose of tissues is nonexistent.²¹⁶ *Greenberg v. Miami Children’s Hospital* also refused to recognize patients’ ownership interest in tissues when researchers defied the patients’ expectations that an affordable treatment would be created from tissue donations.²¹⁷

209. See Catherine M. Valerio Barrard, *Genetic Information and Property Theory*, 87 NW. U. L. REV. 1037, 1061-66 (1993).

210. See *id.* (the value of genetic data to insurers).

211. The property theory argues that the denial of property rights in human tissues and genetic/genomic information is unsustainable when human tissues are valuable tradable objects. See George J. Annas et al., THE GENETIC PRIVACY ACT AND COMMENTARY 67 (1995); Danielle M. Wagner, Comment, *Property Rights in the Human Body: The Commercialization of Organ Transplantation and Biotechnology*, 33 DUQ. L. REV. 931, 934 (1995) (stating that “. . . the right to exclude others from one’s property, which is considered the most important right in the bundle of property rights, is generally present in relation to the human body.”); see also, Judith Jarvis Thomson, THE REALM OF RIGHTS 225 (1990) (stating that property rights are a cluster of rights); Rao, *supra* note 120, at 460.

212. See *Greenberg v. Miami Child. Hosp. Rsch. Inst., Inc.*, 264 F. Supp. 2d 1064, 1072–73, 175 (S.D. Fla. 2003).

213. At common law, no one is allowed to own or sell human tissues. Courts refused to find interests in human body parts on the ground that a cadaver was *nullius in bonis*, and no property existed in a corpse. 3 EDWARD COKE, INSTITUTES OF THE LAWS OF ENGLAND 203 (1644). A designated recipient in organ transplant has no property claim over a donated organ. *Colavito v. N.Y. Organ Donor Network, Inc.*, 860 N.E.2d 713, 719-720 (N.Y. 2006).

A few opinions suggest that either a deceased person, or a medical institution that obtained samples under informed consent, has ownership interest in tissues. See, e.g., *Hecht v. Superior Court*, 16 Cal. App. 4th 836, 850 (1993) (interest in one’s sperm); *Wash. Univ. v. Catalona*, 437 F. Supp. 2d 985, 1002-03 (E.D. Mo. 2006) (ownership over exercised tissues), *aff’d*, 490 F.3d 667, 673 (8th Cir. 2007). A surviving relative can possess the deceased’s body for burial purposes. Samantak Ghosh, *The Taking of Human Biological Products*, 102 CAL. L. REV. 511, 518 (2014).

214. *Moore*, 51 Cal. 3d. 120, 137-38 (1990).

215. *Id.* at 137, 142-47.

216. *Id.*

217. *Greenberg*, 264 F. Supp. 2d at 1072–73.

Professor Ken Gatter considered *Moore* and *Greenberg* as faithful to federal law, which minimally protects tissue donors' interests.²¹⁸ At the center of the plaintiffs' complaint was the defendants' commercial exploitation of research results, rather than the defendants' possession and use of tissues or data.²¹⁹ Thus, *Moore* and *Greenberg* did not show the close connection between the plaintiffs' privacy interest and extracted genetic/genomic data.²²⁰ The plaintiffs did not allege that the defendants invaded their privacy either.²²¹

In contrast, recent court opinions shed some light on genetic/genomic privacy—a nexus between samples and extracted genetic/genomic information.²²² For instance, the Ninth Circuit recognized the connection between a donor's privacy in a blood sample and extracted genetic information and suggested that the blood sample was a convict's property.²²³ Likewise, Justice Mosk's dissent in *Moore* expressed a view that the plaintiff's dignity and sanctity would become nullity when researchers could freely commercialize tissue donors' genetic/genomic information.²²⁴ The Ninth Circuit and Justice Mosk did not formerly accept the property right theory nor did they find a possessory interest for the plaintiffs.²²⁵ However, both recognized essentially the same interest with privacy, after noting the genetic/genomic information was obtained from the analysis of the plaintiffs' tissues and contained a critical part of the plaintiffs' privacy.²²⁶ The

218. Professor Gatter notes *Moore* and *Greenberg*'s failure to appreciate the nexus between the extracted genetic/genomic information and donated tissues. Gatter, *supra* note 75, at 306, 311-18.

219. Gatter, *supra* note 75, at 310-11.

220. *Moore*'s recognition of the doctor's fiduciary duty does not help most research participants and tissue donors because researchers usually do not owe fiduciary duty to them. Also, informed consent is not a modality that allows a claimant to repossess biospecimens. *Moore*, 51 Cal. 3d at 142-47. See also *Greenberg*, 264 F. Supp. 2d at 1072-73 (granting restitution due to the continuing research collaboration that involved the plaintiffs' investment of time and resources).

221. The prevailing view is that property rights are not a proper vehicle for privacy, which is an inalienable interest. J. THOMAS MCCARTHY & ROGER E. SCHECHTER, 2 RIGHTS OF PUBLICITY AND PRIVACY § 10:1 (2d ed. 2019); see generally *Moore*, 51 Cal. 3d 120; *Greenberg*, 264 F. Supp. 2d 1064.

222. E.g., *Moore v. Regents of Univ. of Cal.*, 249 Cal. Rptr. 494, 506-08 (Cal. Ct. App. 1988), *aff'd in part, rev'd in part*, 51 Cal. 3d at 142-47 (Cal. 1990). See Gatter, *supra* note 75 at 311-13 ("the Court of Appeals saw a nexus between *Moore*'s cells and its information.")

223. The Ninth Circuit held that Kriesel was seeking the return of "property" given that the Federal Rule of Criminal Procedure 41(a)(2)(A) defines property as "documents, books, papers, any other tangible objects, and information" *U.S. v. Kriesel*, 720 F.3d 1137, 1144-45 (9th Cir. 2013). The plaintiff requested a return of blood sample, not removal of his DNA profile, created by the use of junk DNA, from the CODIS database. *Kriesel*, 720 F.3d at 1150.

224. Judge Mosk stated that the pertinent inquiry (in a conversion claim) is not whether a patient generally retains an ownership interest in a body part after its removal from his body, but rather whether a patient has a right to determine, before the body part is removed, the use to which the part will be put after removal. Judge Mosk found it clear that a patient does have such right based on his autonomy. *Moore*, 51 Cal. 3d at 174 (1990) (Mosk, J., dissenting).

225. *Kriesel*, 720 F.3d at 1147; *Moore*, 51 Cal. 3d at 160.

226. *Kriesel*, 720 F.3d at 1139-41; *Moore*, 51 Cal. 3d at 174.

plaintiffs' genetic integrity would have been lost if the plaintiffs' tissues and information would have been used disrespectfully.²²⁷

4. Empowerment of Participants

It is firmly established that an individual participant's autonomy and basic rights must be respected in the field of human research.²²⁸ The Nuremberg Code obligates medical professionals to inform patients to arrive at an "understanding and enlightened decision."²²⁹ The Declaration of Helsinki set the standard for informed consent.²³⁰ In the United States, the National Research Act prevents unethical *uninformed* human experiments.²³¹ Autonomy of participants has been the cornerstone of biomedical ethics.²³²

Nonetheless, disputes over the use of biological samples have continued.²³³ To rebuild trust of research participants, studies were carried out to understand how to aid participants' informed decision to participate.²³⁴ The following measures were found to assist informed consent: increased transparency;²³⁵ the reexamination of informed consent taking;²³⁶ the

227. *Moore*, 51 Cal. 3d at 174.

228. ALEXANDER MITSCHERLICH & FRED MIELKE, DOCTORS OF INFAMY: THE STORY OF THE NAZI MEDICAL CRIMES, at xxiii-xxv (Heinz Norden trans., 1949).

229. *Id.*

230. Every precaution should be taken to respect the privacy of the subject, the confidentiality of the patient's information and to minimize the impact of the study on the subject's physical and mental integrity and on the personality of the subject. WORLD MED. ASS'N, *Declaration of Helsinki: Code of Ethics of the World Medical Association*, art. III(3a), G.A. Res. (1964), <http://www.pubmedcentral.nih.gov/picrender.fcgi?artid=1816102&blobtype=pdf>.

231. The National Research Act was devised to prohibit unethical and inhumane treatment of research participants, as experienced in the U.S. Public Health Service Syphilis Study at Tuskegee. National Research Act of 1974, Pub. L. No. 93-348, 88 Stat. 342 (codified as amended in scattered sections of 42 U.S.C.); *The U.S. Public Health Service Syphilis Study at Tuskegee: Research Implications*, CENTERS FOR DISEASE CONTROL AND PREVENTION, <https://www.cdc.gov/tuskegee/after.htm>.

232. *Abdullahi v. Pfizer, Inc.*, 562 F.3d 163, 183-84 (2d Cir. 2009) ("from its origins with the trial of the Nazi doctors at Nuremberg through its evolution in international conventions, agreements, declarations, and domestic laws and regulations, the norm prohibiting nonconsensual medical experimentation on human subjects has become firmly embedded and has secured universal acceptance in the community of nations").

233. Sterling, *supra* note 14, at 113.

234. See, e.g., Yusuf Yazici & Hasan Yazici, *Informed Consent: Time for More Transparency*, 12 ARTHRITIS RES. & THERAPY 121 (2010).

235. See *id.* (consent form disclosure); Akihiko Ozaki et al., *A Call for Improved Transparency in Financial Aspects of Clinical Trials: A Case Study of the CREATE-X Trial in the New England Journal of Medicine*, 36 INVESTIGATIONAL NEW DRUGS 517 (2018) (conflict disclosure); Omer Tene & Jules Polonetsky, *Judged by The Tin Man: Individual Rights in The Age of Big Data*, 11 J. TELECOMM. & HIGH TECH. 351, 366 (2013) (access and transparency); Elizabeth R. Pike, *Securing Sequences: Ensuring Adequate Protections for Genetic Samples in the Age of Big Data*, 37 CARDOZO L. REV. 1977, 2010 (2016) (post-enrollment transparency regarding the law enforcement's access to biobanks).

236. One study found that it is desirable to inform participants about who can access data. It found that over 25 % of the research participants did not remember that they signed an informed consent document to participate and that the majority (54 %) could not correctly identify with whom they had agreed to share their genomic data. Jill Oliver Robinson et al., *Participants' Recall and Understanding of*

engagement of a neutral who acts for participants' interest,²³⁷ and the option to opt-out from research.²³⁸ The United Nations Educational, Scientific and Cultural Organization recommended the establishment of a global vigilance system that provides privacy protection for health information.²³⁹ The enhancement of informed consent will benefit participants and prevent privacy harms.²⁴⁰

The National Academy of Sciences, Engineering, and Medicine recommends sharing research results with participants.²⁴¹ The recommendation is grounded on the understanding that participants' support and trust is crucial to biomedical advancement,²⁴² and the fact that people donate tissues in the expectation that their participation would create better care.²⁴³

In short, the principles of autonomy and informed consent are well-preserved and recognized.²⁴⁴ Improving informed consent with further protection measures minimizes future privacy invasion.²⁴⁵

Genomic Research and Large Scale Data Sharing, 8(4) J. OF EMPIRICAL RSCH. ON HUMAN RSCH. ETHICS 42 (2013); See also Zubin Master & David B. Resnik, *Incorporating Exclusion Clauses into Informed Consent for Biobanking*, 22 CAMBRIDGE Q. HEALTHCARE ETHICS 203, 203 (2013) (exclusion clause in contentious research).

237. See David E. Winickoff & Richard N. Winickoff, *The Charitable Trust as a Model for Genomic Biobanks*, 349 NEW ENGLAND J. OF MED. 1180, 1180 (2003); JESSICA W. BERG ET AL., INFORMED CONSENT LEGAL THEORY AND CLINICAL PRACTICE 297-99 (2nd ed. 2001) (explaining why it is desirable to have a neutral third party to step in for the interests of participants.); Mark A. Hall, *Property, Privacy, and the Pursuit of Interconnected Electronic Medical Records*, 95 IOWA L. REV. 631, 658 (2010); NAT'L ACAD. OF SCIENCES, ENG'G, AND MED., RETURNING INDIVIDUAL RESEARCH RESULTS TO PARTICIPANTS: GUIDANCE FOR A NEW RESEARCH PARADIGM 245 (Jeffrey R. Botkin et al. eds., 2018) (Committee on the Return of Individual-Specific Research Results Generated in Research Laboratories Recommendation) (importance of trust) [hereinafter CRIRR Recommendation].

238. Eric Vermeulen et al., *Opt-out Plus, the Patients' Choice: Preferences of Cancer Patients Concerning Information and Consent Regimen for Future Research With Biological Samples Archived in the Context of Treatment*, 62 J. CLINICAL PATHOLOGY 275, 275-78 (2009).

239. U.N. EDUC., SCI., AND CULTURAL ORG., INT'L BIOETHICS COMM., *Report of the IBC on Big Data and Health*, U.N. Doc. SHS/YES/IBC-24/17/3 Rev.2 (Sep. 15, 2017) (UNESCO-IBC Report), <http://www.unesco.org/new/en/social-and-human-sciences/themes/bioethics/international-bioethics-committee/reports-and-advice>.

240. There are participants who are interested in privacy protective measures adopted by investigators. Alma Husedzinovic et al., *Stakeholders' Perspectives on Biobank-Based Genomic Research: Systematic Review of the Literature*, 23 EUR. J. HUMAN GENETICS 1607 (2015) (the role of information about privacy protection).

241. CRIRR Recommendation, *supra* note 237, at 80.

242. *Id.* at 82.

243. Andrea N. Burnett-Harman et al., *Return of Research-Related Genetic Test Results and Genetic Discrimination Concerns: Facilitators and Barriers of Genetic Research Participation in Diverse Groups*, 23 PUB. HEALTH GENOMICS 59 (2020) (finding that "Respondents willing to participate in genetic research" ranging "from 22% when no results are returned to 87% if health-related genetic results are returned").

244. *Supra* notes 228-30, 235-238.

245. *Supra* note 239, at 22-24.

5. *Quasi-property to Preserve Genetic Integrity*

Granted that tissue donors do not hold property interests in genetic/genomic materials, tissue donors should not be left without remedy.²⁴⁶ Equivalent to the nexus pointed out by the Ninth Circuit and Justice Mosk, *quasi-property* is founded upon the nexus between reproductive tissues or human remains and the dignity of their hosts and family.²⁴⁷ A piece of genetic/genomic information, when it is critical to one's dignity and autonomy, may be recognized as *quasi-property*.²⁴⁸

A *quasi-property* right defends inmost pieces of privacy as they are epitomized in human remains and reproductive tissues.²⁴⁹ *Quasi-property* rights should apply to genetic/genomic information because of its comparable significance.²⁵⁰ In a case where a couple asserted a property right over their frozen pre-zygotes created by in vitro fertilization, the court allowed their recovery based on their property rights.²⁵¹ In *Hecht v. Superior Court*, the Court of Appeal for the Second District of California took a similar position and stated that at the time of death the decedent had ownership interest “to the extent that he had decision making authority” over the use of his sperm.²⁵² Thus, the use of *quasi-property* has been confined to biological materials with special implications—human remains and reproductive tissues.²⁵³ The opinions' reasoning for finding *quasi-property* should be extendable to genetic/genomic information because genetic codes are the source of human development, and no person can live with dignity if his or her genetic integrity

246. *Moore*, 51 Cal.3d at 137, 142-43, 162-63.

247. *See* *Bednarik v. Bednarik*, 18 N.J. Misc. 633, 16 A.2d 80, 89-91 (Ch. 1940) (recognizing a constitutional right to personal privacy and security as well as common law privacy right and denying a petition for compulsory blood test); RESTATEMENT (SECOND) OF TORTS § 652B (1977).

248. Lisa M. Elliott, *Property Rights of Ancient DNA: the Impact of Cultural Importance on the Ownership of Genetic Information*, 16(2) Int'l J. of Cultural Prop. 103, 108-9, 113-14 (2009).

249. Restatement of Tort views *quasi-property* rights as special legal interests of close relatives over human remains of a deceased. RESTATEMENT (SECOND) OF TORTS § 868 (1977) (a judicially created term for the control of a body part).

250. The court afforded damages for the plaintiff when the defendant, a reinternment contractor, recklessly buried a deceased's body in a shallow grave without casket, case, or full headstone. *Sanford v. Ware*, 191 Va. 43, 60 S.E.2d 10, 11-14 (1950). *See also* *Whitehair v. Highland Memory Gardens, Inc.*, 174 W. Va. 458, 460-61, 327 S.E.2d 438, 440-41 (1985) (finding the relative's *quasi-property* right against mishandling of a decedent's body); *Payne v. Alabama Cemetery Ass'n, Inc.*, 413 So.2d 1067, 1068-70 (Ala. 1982) (trespass action by an heir when her mother's body was sinking and destroyed by an omission of a funeral home).

251. *York v. Jones*, 717 F. Supp. 421, 424-27 (E.D. Va. 1989) (finding the “plaintiffs' proprietary” right under a cryopreservation agreement, which stated that the plaintiffs could choose “(1) donation to another infertile couple; (2) donation for approved research; and (3) thawing” if a pregnancy was no more sought).

252. *Hecht v. Superior Court*, 16 Cal. App. 4th 836, 850 (2nd Dist. 1993).

253. *See supra* notes 249-252 and accompanying texts.

is compromised.²⁵⁴ In this day and age, when genetic/genomic technologies can affect one's life, health, dignity, and life planning, a *quasi-property* right should be applicable to genetic/genomic information.

Professor Rao noted that the claim for an embryo, which potentially forms a human being, should be decided under privacy while body tissues that do not develop into a human being can be decided by the property theory.²⁵⁵ Professor Rao's analysis seems to be grounded on the reasonable connection between body tissues and a claimant's personhood and parenthood.²⁵⁶ In other words, a couple can claim *quasi-property* over their embryos that represent their personhood and parenthood.²⁵⁷ Likewise, a pregnant woman or a couple who has been attempting to conceive a child or have conceived a fetus should be free to use genetic testing and obtain genetic/genomic information for medical care and family planning. Likewise, tribal members, who believe in the sacredness of DNA, had a dignitary interest comparable to human remains for blood samples containing genetic/genomic materials because the genetic/genomic materials are an integral part of their personhood.²⁵⁸ In these situations, genetic/genomic information should qualify as *quasi-property*.²⁵⁹

While *quasi-property* changes its form when biological tissues are used to produce data, the protection afforded by *quasi-property* is sufficiently circumscribed.²⁶⁰ First, the information must be essential to the tissue donor's dignity and autonomy.²⁶¹ When genetic/genomic information is too fragmented to be used beyond minimal analysis, the *quasi-property* does not apply because no specific individual can be identified and because it's unlikely to harm the dignity or autonomy of anyone.²⁶² For example, a sequenced short segment of a dementia-related gene (APOE ε4) does not specify from whom the genetic information originates.²⁶³ Even if a sequence

254. See *supra* Sections A, B for why genetic/genomic information has significance upon one's familial and reproductive autonomy and dignity.

255. Radhika Rao, *Property, Privacy, and the Human Body*, 80 B.U. L. REV. 359, 458 (2000) ("In the absence of a relationship between the person and the embryo, however, the embryo may be addressed as an object of ownership governed by the law of property.")

256. See *supra* notes 222-224 and accompanying texts for the nexus between biological samples and genetic/genomic information.

257. Rao, *supra* note 120, at 458-59.

258. See *infra* Argument Section C for the discussion about the ASU Incident.

259. William Boulter, Note, *Sperm, Spleens, and Other Valuables: The Need to Recognize Property Rights in Human Body Parts*, 23 HOFSTRA L. REV. 693, 712 (1995); Megan L. Townsley, Note, *Is There Any Body Out There? A Call For a New Body of Law To Protect Individual Ownership Interests in Tissue Samples Used in Medical Research*, 54 WASHBURN L. J. 683, 683 (2015).

260. See also Moore, 51 Cal.3d at 137.

261. See *supra* notes 249-252 and accompanying texts.

262. Kriesel, 720 F.3d at 1149-50.

263. Paolo Abondio et al., *The Genetic Variability of APOE in Different Human Populations and Its Implications for Longevity*, 10 GENES (BASEL) 222 (2019).

suggests a high probability of developing dementia, the short sequence alone cannot be proclaimed as *quasi-property* because a tissue donor's privacy is likely not endangered by unconsented use of the gene. On the other hand, a court may sustain a privacy action of a tissue donor when a researcher has made a false statement that no genetic information will be collected or used.²⁶⁴

Second, *quasi-property* must be materials that represent a claimant's dignity and autonomy.²⁶⁵ When disputed genetic/genomic information is obtained from someone unrelated to a claimant, the claimant may not claim a *quasi-property* right over the information.²⁶⁶ On the contrary, when a sibling of a claimant has dementia and the sibling's genetic data is used to reveal the inheritance of dementia, the data may be relevant to the claimant's informational privacy.²⁶⁷ Additionally, one tribal member's participation in a genetic study can impact informational privacy of the entire tribal community, as previously discussed.²⁶⁸ In this situation, consultation with the tribe's leader should be considered because other members' autonomy and dignity may be damaged by the study's findings, and the member can understand risks and benefits that are associated with the study participation.²⁶⁹

As such, *quasi-property* rights should apply to genetic/genomic information to a tissue donor's privacy and those related individuals' when the information has ramifications to the procreative, familial, marital, or other highly intimate matters. *Quasi-property* does not require defendants' "highly offensive" acts but requires the nexus between unconsented use of information and the claimant's autonomy and dignity.²⁷⁰

6. Recent Developments to *Quasi-Property*

The logic underlying *quasi-property*—the connection of genetic/genomic information to tissue donors' life-defining choices and their personhood—has resurfaced in privacy cases.²⁷¹ The following opinions demonstrate judicial affirmation of genetic privacy.

264. *Supra* notes 99-100, 102-104 and accompanying texts for the discussion of subject-identifiable information in privacy actions.

265. *Supra* notes 249-252 and accompanying texts.

266. Boulier, *supra* note 259, at 709-10.

267. Because results may show that the claimant has the same genetic mutation responsible for dementia.

268. *See supra* Introduction.

269. *See* NAT'L ACAD. OF SCIENCES, ENG'G, AND MED., AN EXAMINATION OF EMERGING BIOETHICAL ISSUES IN BIOMEDICAL RESEARCH: PROCEEDINGS OF A WORKSHOP 55-60 (2020).

270. RESTATEMENT (SECOND) OF TORTS § 652B.

271. *See infra* Section 6.

A lawsuit filed against Indiana statute “Sex Selective and Disability Abortion Ban” highlighted the nexus between genetic testing and procreative freedom.²⁷² Fetal tissue dispositions were restricted with an abortion motivated by the likelihood of genetic abnormality.²⁷³ The challenger argued that Indiana unconstitutionally restricted the challenger’s freedom to obtain an abortion based on genetic testing and liberty to dispose of excised fetal tissues.²⁷⁴ The District Court for the South District of Indiana found the restrictions unconstitutional under rational basis,²⁷⁵ and the Seventh Circuit’s panel upheld the invalidation.²⁷⁶ Denying the request for en banc review, the Seventh Circuit suggested that rational basis was the wrong standard for a fundamental right of procreative choices.²⁷⁷ Chief Judge Wood indicated that abortion decisions based on genetic abnormalities of a fetus, as well as the right to dispose fetal tissues, are constitutionally protected as fundamental rights.²⁷⁸

The Supreme Court reversed the conclusion on the fetal tissue disposition on the ground that the Seventh Circuit had erroneously applied the rational basis test.²⁷⁹ However, the Court noted that the plaintiffs’ fetal disposal challenge was not argued under the undue burden test and withheld an opinion on the application of the undue burden test in dicta.²⁸⁰ As Justice Ginsburg explained, the incorporation of a pregnant woman’s liberty to control fetal tissue into the constitutional privacy was an expected

272. “PPINK[Planned Parenthood of Indiana & Kentucky] sought declaratory and injunctive relief from” the following: (1) the “‘Sex Selective and Disability Abortion Ban,’ Ind. Code § 16-34-4 (2016), which prohibit a person from performing an abortion if the person knows the woman is seeking an abortion solely for one of the enumerated reasons;” (2) the required step to inform women “[t]hat Indiana does not allow a fetus to be aborted solely because of the fetus’s race, color, national origin, or ancestry, sex, or diagnosis or potential diagnosis of the fetus having Down syndrome or any other disability § 16-34-2-1.1(a)(1)(K);” and (3) the “provisions dealing with the disposal of aborted fetuses”, §§ 16-34-3-4(a); 16-41-16-4(d); 16-41-16-5; 16-41-16-7.6. *Planned Parenthood of Ind. & Ky., Inc. v. Comm’r of the Ind. State Dep’t of Health*, 888 F.3d 300, 302-03 (7th Cir. 2018).

273. *Planned Parenthood of Ind. & Ky., Inc.*, 888 F.3d at 303.

274. *Id.* at 306-07.

275. *Planned Parenthood of Ind. & Ky., Inc. v. Comm’r, Ind. State Dep’t of Health*, 265 F. Supp. 3d 859, 862-63, 871-72 (S.D. Ind. 2017) (invalidating the fetal tissue regulation for lack of legitimate interest under rational basis), *aff’d per curiam*, 888 F.3d 300, *rev’d with regards to the fetal disposition provision*, *Box v. Planned Parenthood of Ind. & Ky., Inc.*, 139 S. Ct. 1780 (2019).

276. *Planned Parenthood of Ind. & Ky., Inc.*, 888 F.3d at 308-09, *rev’d with regards to the fetal disposition provision Box*, 139 S. Ct. 1780.

277. *Planned Parenthood of Ind. & Ky., Inc. v. Comm’r of the Ind. State Dep’t of Health*, 917 F.3d 532, 535-36 (7th Cir. 2018) (per curiam) (denying en banc hearing and stating that the court was bound by the arguments made by the parties); *see also Box*, 139 S. Ct. 1780 (Ginsburg, J., concurring) (“I would not summarily reverse a judgment when application of the proper standard would likely yield restoration of the judgment.”).

278. *Planned Parenthood of Ind. & Ky., Inc.*, 917 F.3d at 534.

279. *Box*, 139 S. Ct. at 1782.

280. *Box*, 139 S. Ct. at 1782 (“This case, as litigated, therefore does not implicate our cases applying the undue burden test to abortion regulations.”).

development from previous decisions since the constitutional privacy has been afforded to liberties essential to a person's autonomy and dignity.²⁸¹ These liberties include liberty in marriage, abortion, reproduction, and sexual activity.²⁸² Just like *quasi-property*, which resides in matters imperative to a familial relationship and a family's dignity, the Court should offer constitutional protection for the recovery of a fetal tissue from an actor who tarnishes the plaintiff's protected dignity and autonomy.²⁸³

Freedom to obtain genetic information has been recognized, insofar as the court decided the claimants had standing, as a constitutional liberty, which furthers the freedom to control fetal tissues.²⁸⁴ The Sixth Circuit indicated that a parent has a right to control and use genetic information taken from neonatal screening.²⁸⁵ The court suggested that strict scrutiny should apply to the parent's right to use genetic information for care of a child.²⁸⁶

Based on the preceding discussion, freedom to access and control fetal genetic/genomic information and freedom to dispose of fetal tissues are recognized as constitutionally protected liberties.²⁸⁷ Given the significance of genetic/genomic information to a person's health, procreation, and family relationship, freedom to use genetic/genomic information deserves legal protections. While courts did not mention "*quasi-property*," the logic behind the above opinions coincides with *quasi-property*.²⁸⁸ The liberty to control one's own and one's child's genetic/genomic information is a matter of constitutional privacy because it is a linchpin to our personal values, procreative choices, bodily integrity, and familial health.²⁸⁹ Under the Fourteenth Amendment, the state is prohibited from imposing undue restrictions upon the plaintiffs' fundamental rights of privacy.²⁹⁰

281. *Id.* at 1792.

282. *Id.*; *City of Akron*, 462 U.S. at 427; *Roe*, 410 U.S. at 169-70 (Stewart, J., concurring).

283. *Box*, 139 S. Ct. at 1781.

284. *Kanuszewski v. Mich. HHS*, 927 F.3d 396, 409-11 (6th Cir. 2019).

285. *Id.* (finding a child's standing to seek injunctive and declaratory relief, as well as damages, in connection with Fourth and Fourteenth Amendment claims relating to the transfer and storage of a blood sample). *But see* *Laporte v. Gordon*, 2020 WL 1429496 (E.D. Mich. Mar. 24, 2020) (finding the special needs doctrine exception to the Fourth Amendment).

286. *Kanuszewski*, 927 F.3d at 419.

287. *See Planned Parenthood of Ind. & Ky., Inc.*, 265 F. Supp. 3d at 869, *aff'd per curiam*, 888 F.3d 300, *rev'd with regards to the fetal disposition provision*; *Box*, 139 S. Ct. at 1782 (reversing the Seventh Circuit's opinion on the fetal tissue disposition based on Indiana's legitimate interest). *But see Box*, at 1786-87 (Thomas, J., concurring) (explaining the limitation to a parent's abortion right based on the fetal genetic abnormality).

288. RESTATEMENT (SECOND) OF TORTS § 868 cmt. a.

289. U.S. CONST. amend. XIV.

290. *See generally Doe*, 410 U.S. 179; *Roe*, 410 U.S. 113; *Eisenstadt*, 405 U.S. 438; *City of Akron v. Akron Ctr. for Reprod. Health, Inc.*, 462 U.S. 416, 427 (1983); *Casey*, 505 U.S. at 883-84.

7. Summary

Quasi-property rights arise from matters of genetic significance, such as reproductive tissues, and ancestral remains.²⁹¹ Granting *quasi-property* rights resemble the protection from fundamental rights of privacy.²⁹² Both *quasi-property* and privacy rights should extend to such genetic/genomic information that is integral to a person's dignity and autonomy. *Quasi-property* claims are, therefore, only allowed for information tightly attached to the claimant's privacy while affording sufficient protection.²⁹³

The next section will project the *quasi-property* theory onto the ASU Incident and the senator's DNA test and discuss how to identify genetic/genomic information that has a nexus to tissue donors' autonomy and dignity.²⁹⁴

C. Arizona State University Lawsuit

1. Facts of the Case and Traditional Privacy Law

In 1989, Havasupai Tribe consulted a professor of ASU with regard to the increasing disease burden caused by diabetes.²⁹⁵ The professor proposed a tribe-wide genetic study as a means to determine the genetic basis of diabetes among Havasupai Tribe.²⁹⁶ The professor's fellow geneticist, who was interested in genetic causes of schizophrenia, agreed to be a primary investigator.²⁹⁷ The tribe decided to participate in the study, and members gave written or oral consent to the study participation.²⁹⁸ The signed consent forms ambiguously stated that collected samples would be used for research on "behavioral/medical disorders" while the tribe members did not know that samples would be used for purposes other than diabetes research.²⁹⁹

The geneticist examined samples to find a genetic basis for conditions such as schizophrenia and performed a migration study without specifically seeking consent from the tribe or the members.³⁰⁰ The rate of inbreeding

291. RESTATEMENT (SECOND) OF TORTS § 868 cmt. a.

292. See *supra* note 290.

293. See UNESCO-IBC Report, *supra* note 175; Celia B. Fisher & Deborah M. Layman, *Genomics, Big Data, and Broad Consent*, 19 PREVENTION SCI. 871, 876 (2018) ("The extent to which unspecified secondary use of biospecimens can pose a social risk to already vulnerable populations is difficult to anticipate or describe in broad consent procedures.").

294. See *infra* Section C.

295. Van Assche et al., *supra* note 14, at 56-57.

296. *Id.*

297. *Id.*

298. Van Assche et al., *supra* note 14, at 57. Professor Markow, the geneticist who conducted Havasupai genetic study, applied for and obtained funding to study schizophrenia. It was not disclosed to participants. Van Assche et al., *supra* note 14, at 57.

299. *Id.*

300. *Id.*

within the tribe and their genetic distances to other populations were published.³⁰¹ Moreover, the geneticist sent blood samples to her new institution despite conflicting provisions in the consent form.³⁰² These facts were ultimately discovered by Havasupai Tribe.³⁰³

Havasupai Tribe demanded immediate termination of the genetic research.³⁰⁴ When the parties failed to reach an amicable solution, the tribe sued ASU and the researchers for breach of fiduciary duty, fraud, a violation of informed consent, and conversion.³⁰⁵ Some claims were dismissed, but the breach of fiduciary duty and other state claims remained.³⁰⁶ Faced with years of litigation, ASU agreed to pay \$700,000 to the tribe and to return all the samples and obtained information.³⁰⁷

Had the parties not settled, the court would have decided on the defendants' contention that they had obtained broad consent and that they had used coded samples without personal identifiers.³⁰⁸ Although ASU's \$700,000 settlement may not quantify ASU's anticipated losses, it is clear that ASU was motivated to settle.³⁰⁹

As discussed earlier, the substitution of specific informed consent with broad consent may seriously tarnish tissue donors' autonomy when the tissue donors are not informed of the nature of additional studies.³¹⁰ Moreover, the presence of consent does not always exclude a privacy claim because the scope of consent and the validity of consent are distinct issues.³¹¹ The tribe leaders and the participants were not informed about the geneticist's

301. See *Havasupai Tribe v. Ariz. Bd. of Regents*, 204 P.3d 1063, 1067 (Ariz. Ct. App. 2008) ("at least four doctoral dissertations and various academic papers, some of which concerned evolutionary genetics, rather than medical genetics") *denying review in part, granting in part*; *Havasupai Tribe v. ABoR*, No. CV-09-0007-PR, 2009 Ariz. LEXIS 82, at *1 (Apr. 20, 2009); Therese A. Markow et al., *HLA Polymorphism in the Havasupai: Evidence for Balancing Selection*, 53 AM. J. HUMAN GENETICS 943 (1993); Therese A. Markow & John F. Martin, *Inbreeding and Developmental Stability in a Small Human Population*, 20 ANNALS HUMAN BIOLOGY 389 (1993); Tatiana M. Karafet et al., *Y Chromosome Markers and Trans-Bering Strait Dispersals*, 102 AM. J. PHYSICAL ANTHROPOLOGY 301 (1997).

302. The researchers argued that since those samples were coded and individual donors could not be identified, no information had left ASU. Van Assche et al., *supra* note 14, at 59.

303. *Havasupai Tribe*, 204 P.3d at 1068.

304. A notice of claim to ASU and the geneticist indicated that "ASU's actions have invaded the personal privacy of Havasupai tribal members and the cultural and religious privacy of the Havasupai Tribe." *Havasupai Tribe*, 204 P.3d at 1068.

305. See *Tilousi v. Ariz. State Univ. Bd. of Regents*, No. 04-CV-1290-PCT-FJM, 2005 WL 6199562 (D. Ariz. Mar. 3, 2005) (Slip Op.); *Havasupai Tribe*, 204 P.3d at 1069-70; Debra Harry, *Indigenous Peoples and Gene Disputes*, 84 CHI.-KENT. L. REV. 147, 152 (2009).

306. *Havasupai Tribe*, 204 P.3d at 1069-70.

307. Van Assche et al., *supra* note 14, at 61-62.

308. *Id.* at 74-75.

309. The informed consent claim may not have succeeded depending on the jurisdiction given that some of the defendants lacked a doctor-patient relationship. See *supra* Argument Sections A, B.

310. See *infra* Argument Section B for the discussion of broad consent.

311. See *Grimes v. Kennedy Krieger Inst., Inc.*, 366 Md. 29, 98 (2001); *Anderson v. Jones*, 606 A.2d 185, 187-88 (D.C. 1992).

immigration study and inbreeding study.³¹² No member would have likely participated in the research if they had been informed. The researchers' consent-based arguments must have failed.

Another point of contention, the de-identification of samples, seems easier to decide. When determining whether an exception from the informed consent requirement applies, it is a key consideration under the Common Rule.³¹³ The geneticists may have believed that their compliance with the Common Rule had resolved all the issues. Nevertheless, the court could have found that the migration study and the inbreeding study had harmed the plaintiffs' privacy given that the studies had involved sufficiently limited, potentially traceable participants. Also, the Third Circuit's logic in the network privacy case, if followed, would have eliminated the identifiability test subjects from a contestable issue, especially when participants were misled by defendants' statements.³¹⁴

Privacy invasions are highly offensive to reasonable persons.³¹⁵ The offensiveness of an intrusion is measured by factors such as the "likelihood of serious harm to the victim", the degree and setting of the intrusion, the intruder's motives and objectives, and whether countervailing interests or social norms render the intrusion inoffensive.³¹⁶ ASU's researchers used samples for purely academic purposes.³¹⁷ The researchers obtained broad consent forms from 100 participants and stopped using broad consent forms because the document-based process did not help the participants' understanding of genetic/genomic research.³¹⁸ These facts may have offset "offensiveness" of the defendants' acts to some degree. Accordingly, the plaintiffs' privacy invasion claims may have faced a few difficulties in alleging a prima facie case.³¹⁹

2. Application of Quasi-Property

Unlike the more relaxed identifiability requirement in privacy actions, *quasi-property* claims require the identifiability of data subjects or the nexus between human tissues and privacy interests.³²⁰ Accordingly, *quasi-property* claims would not have succeeded as to the collected genetic/genomic information because it was de-identified. On the other hand, the blood

312. Van Assche et al., *supra* note 14, at 58-59.

313. See 42 U.S.C. § 241 (d)(4) (2012).

314. *In re Nickelodeon Consumer Privacy Litig.*, 827 F.3d at 294. See *supra* Argument Section A.

315. See *supra* Argument Section A.

316. See *supra* Argument Section A; *supra* note 98.

317. Van Assche et al., *supra* note 14, at 57.

318. *Id.*

319. *Havasupai Tribe*, 204 P.3d at 1078 ("general damages", which by nature are subjective, deeply personal and often difficult to quantify.).

320. See *supra* Argument Section B. 5.

samples contained enough DNA elements for the participants' identification could have constituted the tribe members' *quasi-property* because the blood samples were thought to be equivalent to their sacred body.³²¹

The unauthorized use of blood samples can harm the participants' dignity and decision-making in their familial or life planning matters, especially under the circumstance of the ASU Incident.³²² The researchers at ASU analyzed the blood samples to determine the tribe's migration and inbreeding without providing information or seeking specific authorization.³²³ Because the tribe considers DNA as a part of a person,³²⁴ the research should have respected the tribe's core values and dignity and the autonomy of the tribal relationship.³²⁵ Hence, under *quasi-property*, the plaintiffs could have sought return of their samples, in addition to damages, on the ground that the unauthorized DNA analysis and the disclosure harmed their dignity and autonomy³²⁶ regardless of whether broad consent existed or whether the defendants did it solely for academic purposes.³²⁷

The estimated outcome under *quasi-property* parallels the actual resolution of the case. While privacy claims would have been contestable, *quasi-property* could have realized an effective resolution.

D. Senator's DNA Test v. Cherokee Nation's Legacy

1. Facts of the Case and Traditional Privacy Law

Regarding Senator Warren's DNA test, her privacy was not at the heart of the controversy.³²⁸ The Cherokee Nation's self-governance was one of the privacy interests allegedly disturbed by the senator's DNA testing.³²⁹ Assuming members of the Cherokee Nation hold informational privacy interests in their blood samples and information, what arguments could the Cherokee Nation or their members have made? Would the Cherokee Nation or their members have successfully pursued a privacy action? What about a *quasi-property* claim to block the senator's use of DNA testing or to prevent a testing company's use of DNA and information?

321. Van Assche et al., *supra* note 14, at 56.

322. *See supra* Argument Section A.

323. *Havasupai Tribe*, 204 P.3d at 1076 (“an additional unauthorized test . . . can be sufficient to state a claim for relief for intrusion upon seclusion.”) (quoting *Doe v. High-Tech Inst., Inc.*, 972 P.2d 1060, 1068 (Colo. App. 1998)).

324. *Petit, supra* note 3.

325. *Id.*

326. Van Assche et al., *supra* note 14, at 55.

327. *See supra* Argument Section A.

328. Kessler, *supra* note 1. The senator would not have received protection for her widely published test results.

329. *Petit, supra* note 3.

Regarding the privacy invasion claim against the senator, it is unlikely that the court would have found any invasion because the senator herself took the DNA test and did not take any sample or confidential information from a member of the Cherokee Nation.³³⁰ Additionally, the senator did not attempt to intervene in the tribe's determination of citizenship.³³¹ The disclosure of her DNA test may not have been considered a threat to the tribe's privacy. The disclosed information was only a conclusion of the testing company in contrast to a situation where the member's genetic sequence was obtained and published as evidence.³³² The court would have denied the claim of privacy invasion against the senator.³³³ Even if privacy invasion had existed, the senator's action would not have been "highly offensive to a reasonable person" because the senator had a legitimate reason for taking a DNA test to know her ancestry.³³⁴ Thus, the court likely would not have returned a favorable ruling for the Cherokee Nation or its members.

Similarly, a privacy invasion claim against the testing company may not have succeeded. If the company had obtained a DNA sample of a tribal member, and had used it against the member's will, it may have constituted a privacy invasion.³³⁵ However, it is probable that the company would use information in the public domain. In such a case, the use of information would not have been found to be an intentional invasion of the donor's privacy given that no intentional attack on the donor's privacy would have been found.³³⁶

As with the ASU Incident, the lack of highly offensive conduct would have been another reason to dismiss the claim.³³⁷ Also, the issue of identifiability of a tissue donor and the existence of a tissue donor's consent could have complicated the tribe's case.³³⁸ However, the identifiability and the consent are fact dependent issues.³³⁹ As with the ASU Incident, these are often not dispositive.

In sum, the tribe and its members would not have succeeded in privacy invasion claims against the senator. Also, the claims against the testing

330. Kessler, *supra* note 1. The genetic testing company that offered DNA testing to the senator may have obtained ancestry information from public sources.

331. Kessler, *supra* note 1.

332. *Id.*; Van Assche et al., *supra* note 14, at 55.

333. *See supra* Argument Section A.

334. *See supra* notes 1-3 and accompanying texts.

335. *In re Nickelodeon Consumer Privacy Litig.*, 827 F.3d at 293-294. *See supra* Argument Section A.

336. There is no intentional unauthorized use of data. *See supra* notes 94-98 and accompanying texts.

337. Van Assche et al., *supra* note 14.

338. *See supra* Argument Section A.

339. *Id.*

company may have failed as well due to a lack of an intentional privacy invasion.

2. *Quasi-property claim*

Quasi-property protects a tissue donor's dignity and autonomy in familial, procreative, or life planning matters.³⁴⁰ If the company possesses DNA samples taken from members of the Cherokee Nation, and uses them for commercial purposes, the member's rights, under a *quasi-property* theory, may have been a basis for a favorable result for the tribe.³⁴¹

The member may have held a *quasi-property* right in the sample given that the member probably considers the ancestry information a part of the self and as valuable as information related to family planning matters. Upon proving that the commercial use of the sample conflicted with the member's core privacy values, the member should have been able to suspend offensive uses.

By contrast, if the company did not have any sample or identifiable information about the member, *quasi-property* claims may not have prevailed because *quasi-property* does not extend to de-identified information.³⁴² Thus, members' *quasi-property* claims concerning identifiable information may have been successful.

The tribe's interest in connection to the company's DNA testing presents a challenging issue. In one aspect, the tribe, as a group, may have owned a certain privacy interest over samples and genetic/genomic information taken from the tribe members. However, it is unclear how the genetic testing concerned familial, procreative, or life planning matters of the tribe.³⁴³ Also, since *quasi-property* is a possessory interest, its right holder should be a person having a close relationship to the object.³⁴⁴ In this circumstance, the member who donated the tissue, if the member were still alive, should be considered such a person.

Thus, with respect to *quasi-property*, individual members of the Cherokee Nation could have regained their genetic materials or subject-identifiable information, not the tribe. The tribe may have a supportive role in realizing the relief to its members.

340. See *supra* Argument Sections A, B.

341. See *supra* Argument Sections B.

342. See *supra* Argument Section B.

343. See *supra* note 4 and accompanying texts.

344. RESTATEMENT (SECOND) OF TORTS § 868 cmt. a.

E. Decisions to Use or Not to Use

The ASU Incident illustrates why genetic/genomic information obtained from human tissues should be protected from unauthorized use and disclosure.³⁴⁵ Senator Warren's apology to the Cherokee Nation reminded us of the conflict among different interests in using or not using genetic/genomic information.³⁴⁶ *Quasi-property* fills the gap left by other approaches.³⁴⁷ *Quasi-property* provides protection for genetic/genomic information when there is a nexus between the substance and dignity and the autonomy of a tissue donor.³⁴⁸

CONCLUSION

Genetic/genomic information is a source of scientific advancement and a source of controversy. Unconsented use of genetic/genomic information can stigmatize tissue donors and affects numerous stakeholders. Privacy tort claims are largely ineffective against genetic/genomic research conductors. *Quasi-property* rights strike the right balance among conflicting interests and defend a key piece of privacy epitomized in human tissues and genetic/genomic information. Recent opinions suggest that *quasi-property* should be available for tissue donors who seek recovery of materials and information that are essential to their dignity.³⁴⁹

345. *See supra* Argument Section C.

346. *See supra* Argument Section D.

347. *See supra* Argument Section B.

348. *Id.*

349. *Id.*